UNIVERSITY OF CAPE TOWN
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The Impact of African Traditional Healers on Antiretroviral (ARV) Treatment in South Africa

Sumaya Mall

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Supervisors: Prof L London
Prof N Nattrass

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Abstract

There are few studies on the impact of African traditional healing on HIV/AIDS care and treatment in South Africa. There is a need for concrete data on the subject as many people across the African continent are thought to be accessing these kinds of healing services. This study which consists of three inter related sub studies, investigated the impact of African traditional healers on Antiretroviral (ARV) treatment in South Africa. Each of the sub studies focused on the insights and opinions of three different populations, i.e. health care workers, traditional healers (who were affiliated with HIV/AIDS care services) and HIV positive patients.

The first of the sub studies used in- depth interviews to explore the attitudes and approaches of ten health care professionals (nurses, doctors, ARV counsellors and a pharmacy assistant) working in ARV roll out sites in South Africa to their patients taking traditional medicine and accessing traditional healing paradigms. The sub study also probed their opinions of collaborating with traditional healers to strengthen ARV care. Furthermore, this sub study included two focus group discussions with lay health workers at two ARV sites (i.e. ARV counsellors and patient advocates). On the whole the study showed that health care professionals are concerned about the possibility of traditional healers undermining an ARV roll out programme. These perceptions are based on concerns that traditional healers may provide untested substances to HIV positive patients that could interact adversely with ARV drugs. They also believed that traditional healers could discourage patients from adhering to their ARV regimen. However, despite these concerns, most of the health care professionals were willing to collaborate with traditional healers but the partnership would have to be formed on the basis of the principles of the biomedical paradigm of healing. Health care

professionals preferred to be solely in charge of the ARV drug regimen with (biomedically) trained traditional healers supporting them. They preferred traditional healers to concentrate solely on symbolic rituals. The focus groups with the ARV counsellors and patient advocates show that these lay health workers support an ARV roll out process that effectively underplays the role of traditional healers and therefore actively discourage their patients from using traditional healing services while taking ARV treatment.

The second sub study complements the first and used in-depth interviews to explore the attitudes and approaches of five female traditional healers (working in HIV/AIDS organizations in the Western Cape) towards the use of ARV treatment by their clients. This study also explored their attitudes towards a partnership with the formal public health sector with regard to HIV/AIDS care. The sub study showed that traditional healers are concerned about the well being of HIV positive people. All of the traditional healers who were recruited into this study were in favour of a partnership with health care workers as long as such a partnership is based on mutual collaboration and respect.

The third sub study was a study of HIV positive patients attending health facilities that provide ARV care. A semi structured questionnaire was adapted from instruments used in previous studies and was complemented by in depth interviews with patients who reported use of traditional healing systems in the past year. This sub study explored the attitudes of the respondents towards African traditional healers and their practices. The responses of the patients show that the majority of respondents have never accessed a traditional healing service. Some of the patients recruited in the study said they had accessed a traditional healing service before they had begun ARV treatment or before they were recruited into this study. They expressed the reasons for their choice. Only two patients were found to be

actively crossing between ARV treatment facilities and traditional healing services at the time of their interview. A public health and human rights analysis suggests means of incorporating a traditional healer in ARV care, whereby an ARV treatment policy can respect cultural rights of patients and traditional healers while simultaneously improving ARV treatment infrastructure. Limitations encountered in the study such as location of the research sites, nature of the respondents and the ways in which the questions were worded to the respondents were addressed through efforts by the researcher. The study concludes that a partnership between traditional healers and the formal public health sector is feasible but must incorporate respect for cultural rights.

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Glossary of Acronyms

Term	Acronym
Antiretroviral Drug	ARV
Tuberculosis	TB
Voluntary Counselling and Testing	VCT
Sexually Transmitted Infections	STI
World Health Organization	WHO
Directly Observed Treatment Short Course	DOTS
Multidrug Resistant Tuberculosis	MDR TB
Extremely Drug Resistant Tuberculosis	XDR TB
Traditional Healers Organization	THO

Chapter 1: Background and Rationale

In 2006 it was estimated that the national prevalence rate of HIV/AIDS in South Africa was 11% (5.4 million people out of a total population of 48 million were thought to be HIV positive and 600 000 sick with full blown AIDS) (Dorrington et al, 2006). The magnitude of the HIV/AIDS epidemic is thus vast and has resulted in serious challenges for the South African public health system including stigma and discrimination against HIV positive people (Maughan-Brown, 2007). Along with diverse cultural beliefs of illness aetiology which are potentially antithetical to biological theories, these issues impact on disease pathogenesis in different ways. One serious consequence is that they can potentially lead to poor adherence to Antiretroviral (ARV) therapy. Although there are studies conducted in South Africa that have found good adherence rates (Orrell et al, 2003), there are also studies that have produced contrasting results and found that adherence to ARV therapy can be variable or poor (Gill, 2005 and Weiser et al, 2003).

African traditional healing is a paradigm that is often discussed in relation to ARV treatment adherence. Traditional healers who provide a multitude of health related services (e.g. diagnosis, clairvoyance, divining) (Ngubane, 1981) are readily available to people who are not accessing conventional public health care and can well discourage people from taking their ARV treatment to fully immerse in traditional healing and what it has to offer (Kiguba, 2007). Furthermore traditional medicines are generally untested (Homsy et al, 2004) and there are potential problems for patients who opt to take ARV treatment and traditional medicine concurrently. There are known adverse interactions between many ARV and African traditional drugs. For example, although the African traditional drug, St Johns Wort

has known antiviral properties (Cass, 1998) it has been shown to interact adversely with the ARV drugs nevirapine and efavirenz as it reduces the concentration of the ARV drugs in the bloodstream quite significantly. This kind of interaction could potentially result in clinical failure or rapid resistance to the ARV drug regimen (Liverpool HIV Pharmacology Group, 2007)

In South Africa, 70% of people with HIV/AIDS or people who suffer from other sexually transmitted infections (STI) are thought to be accessing traditional healing services (Wreford, 2005 a). This figure can be partly attributed to the apartheid system when the majority of the population were denied adequate health care. They were thus often dependent on traditional remedies made from herbs and roots (Foyaca-Sibat, 2005). However, even in democratic South Africa, lack of access to adequate health care services is problematic especially for the vast majority of HIV positive people, many of who are of lower socio economic status. Those who cannot or who refuse to take ARV drugs may opt to take traditional medication instead. They may struggle with issues of affordability or could well believe that traditional healing can offer a cure for HIV/AIDS (Nattrass, 2005: a).

The use of traditional healing methods also has implications for the protection of human rights in South Africa. The South African Constitution was adopted in 1996 to uphold the freedom and dignity of all citizens and states that people have the right to enjoy their culture (South African Constitution, 1996). The right to use traditional medicine or practise traditional healing may be viewed as part of this right to culture. However, within a broader public health or a treatment context, this right can be limited if exercising cultural rights impacts negatively on other individuals' rights.

This safeguarding of human rights can result in tension between public health objectives and human rights. Human rights analysts argue that it is essential that public health policies incorporate a human rights element (Mann et al, 1999). With regard to HIV/AIDS HIV positive people are viewed as vulnerable to stigma and discrimination and governments are responsible for protecting them from any violations of their rights. The arguments of two renowned analysts in the field are briefly presented below:

De Cock et al (2002) argue that human rights approaches to the HIV/AIDS epidemic can potentially limit 'the role of public health and social justice, which offer a more applied and practical framework in Africa's devastating epidemic' (Gruskin and Loff, 2002:1880). De Cock et al (2002) are of the view that the African continent has been poorly served by a human rights approach to HIV/AIDS but would rather benefit greatly from a public health approach to HIV/AIDS that incorporates voluntary counselling and testing (VCT), routine HIV screening, treatment for sexually transmitted infections, routine diagnostic HIV testing for patients seeking medical treatment (e.g. for tuberculosis) and improved access to HIV/AIDS treatment. Gruskin and Loff (2002) argue in response to de Cock (2002) that introducing human rights into public health work is 'about processes and their application towards public health gains'. They extend their argument by stating that although sometimes public health policies can potentially restrict human rights, stating the objectives and the justification for the restriction would help reduce conflict between public health and human rights.

Allowing for use of traditional medicine by these HIV positive patients could potentially undermine an ARV roll out especially if patients do not adhere to their treatment in order to prioritise traditional medicine. On the other hand, there is a possibility that traditional healers

can potentially contribute positively to the public health system in South Africa by encouraging patients to take their ARV treatment properly. They could strengthen an ARV roll out process and including them in the public health sector's HIV/AIDS care programme can be regarded as an attempt towards protecting human rights. It is also a means of promoting public health objectives. Respect for human rights could thus be synergistic with both the realisation of the right of access to health care and broader public health objectives for HIV/AIDS control (Mann et al, 1999).

This thesis describes the findings of an exploratory study that investigated the impact of African traditional healers on ARV treatment in South Africa. The study comprises three sub studies: one of health care workers, one of traditional healers who have experience with HIV patients and lastly one of HIV positive (both pre treatment and treatment) patients. Chiefly, a qualitative methodology was used in the study but the patient study consists of a quantitative arm with qualitative data from some open ended questions.

Objectives of the study were:

(1) Health workers study: To describe:

- The attitudes of health care professionals to the use of traditional healing paradigms by ARV patients and towards possible collaborations with traditional healers.
- The advice the health care professionals give their patients about using these systems

(2) Traditional Healers Study: To describe:

- the attitudes of traditional healers to the use of clinical or biomedical health systems by their clients and towards possible collaborations with medical doctors.

- the advice they give their patients about using these systems

(3) Patient Study: To describe:

- the attitudes to and the experiences of ARV patients to traditional healers including the experiences of patients crossing between the two paradigms of healing.
- the impact of traditional healers on their adherence to the drug regimen

4) Human Rights Analysis

- To explore whether the pursuit of cultural beliefs and practices cause conflict with public health care system objectives.

- To develop recommendations for a public health policy that respects and protects cultural rights and dignity and ensures non discrimination.

Chapter 2: Literature Review

The Electronic databases PUBMED and the Cochrane library were scanned for studies that have probed aspects of the intersection between African traditional healing and HIV/AIDS. A specific, narrow search strategy was used using the search terms 'African traditional healing' and 'HIV/AIDS'. A number of studies were then identified. In turn, the bibliographies of many of these studies yielded additional useful sources. With regard to the human rights element of the study, the work of well known analysts and theorists was extracted. Further relevant sources were accessed through recommendations by colleagues who work in the area of HIV/AIDS research. Three prominent themes from the literature sources were subsequently identified as relevant to the study:

1) The influence of patient beliefs of illness aetiology (e.g. the witchcraft paradigm) on health seeking behaviour.
2) Lessons learnt from previous collaborations with traditional healers
3) The intersection between public health and human rights and how this relates to traditional healing and ARV treatment.

Patient Beliefs

Studies of patient beliefs of illness aetiology are frequent in the medical, psychological and anthropological literature. These studies illustrate a range of cultural interpretations of illness aetiology. For example, illness can be viewed as consequences of the anger of the ancestors (Abdool Karim, 2004) or as the consequence of witchcraft (idiliso) (Ashforth, 2001). Witchcraft has been a common interpretation of the symptoms of HIV/AIDS in many rural

parts of African countries. Interestingly witchcraft has from time to time been assimilated into scientific explanations for disease aetiology (Iliffe, 2006). 'People might believe simultaneously, for example, that tiny insects caused the disease but that witchcraft explained why it infected them.' (Iliffe, 2006:92). Iliffe's point about hybrid explanations of illness aetiology can be applied to the findings of Gelfand (1967) in Nattrass (2005 b). This study found that patients in a Namibian township crossed between the two systems of healing (i.e. clinical services and traditional healing services). They generally reported a preference for a clinical service but said they would consult a traditional healer when suffering from epilepsy, infertility, intestinal problems and mental health problems.

Edington et al (2002) conducted a study of beliefs of tuberculosis (TB) aetiology in a rural district of South Africa. The study found that a belief that cultural rules have been broken (either after the death of a family member or a miscarriage) was frequently associated with a positive TB diagnosis. 'The resulting disease is believed to be adequately treated by traditional healers' (Edington et al, 2002:1075). A study conducted in the Transkei region of South Africa found that neurocystierocis, an infection of the central nervous system, and causative agent of epilepsy was believed to be caused by evil forces. Thus it was believed that this infection can be treated adequately by common traditional healing methods of shaking the bones and appealing to the ancestors for advice (Foyaca-Sibat, 2005).

Similarly patient beliefs of HIV/AIDS aetiology are as significant in influencing treatment strategy as the other infectious diseases described above. Nattrass and Ashforth (2005) describe the challenges faced by Voluntary Counselling and Testing (VCT) workers in Kwa Zulu Natal, South Africa. These counsellors have heard four prominent everyday metaphors for HIV infection, general illness and the immune system from their clients. Illness is

believed to be caused by pollution and (HIV) infection is regarded as a form of warfare or a foreign army attacking the body's immune system (soldiers or amasojha in Zulu). In the case of the former, some of these forms of pollution are regarded as caused by breach of moral codes while others are regarded as 'the result of more mundane encounters with filth' (Ashforth, 2005 in Nattrass & Ashforth, 2005: 286). These counsellors have also heard a comparison of HIV with dirt. In this case, ARV treatment is referred to as a cleaning detergent or agent (Nattrass and Ashforth, 2005).

Previous Collaborations with Traditional Healers

Traditional healers are available to those in need of health care. However, formally trained health workers are often reluctant to collaborate with traditional healers. This may be due to the common association of these healers with witchcraft practices or they may believe that there is too wide a rift between traditional healing and biomedicine. In turn, traditional healers also feel that they were marginalised during the colonial period and thus express tentativeness at the possibility of collaborating with the formal health sector (Wreford b, 2005).

Despite the friction between traditional healers and formally trained health professionals, a number of studies have explored the possibility of integrating traditional healers into formal HIV/AIDS prevention and treatment programmes.

Peltzer et al (2006) found in their controlled trial in Kwa Zulu Natal, South Africa that although traditional healers may be aware of basic information about HIV/AIDS there are

still vast differences between their healing paradigm and that of biomedicine. There were traditional healers recruited in this study who were of the belief that there is a cure for HIV/AIDS. Others were implementing potentially unsafe practices (e.g. blood letting and using the same blade on many different patients), risky practices in the age of HIV/AIDS.

However there are also studies that point out that there are also potential benefits that can be derived from collaboration between formal health workers and traditional healers.

In Uganda and the Gambia, health interventions have successfully incorporated traditional healers into psychiatric, tuberculosis (TB) and obstetric health services. Uganda has also included licensed traditional healers in VCT programmes and has trained traditional healers in psycho social care for HIV positive patients (Iliffe, 2006). In Uganda, political leaders are of the view that traditional healers are useful in public health interventions if 'armed with the right information' (Illife, 2006: 45). Ugandan president, Yoweri Museveni is of the opinion that as neither modern medicine nor traditional healing has found a cure for HIV/AIDS, the two healing paradigms can learn from one another (Iliffe, 2006).

In South Africa, from as early as the 1970s, traditional healers were participating in control programmes of sexually transmitted infections (STI). In late 1992, an HIV prevention programme taught traditional healers the main transmission routes of HIV/AIDS as well as the characteristics of prevention strategies such as condom usage (Green, 1995). Harper et al (2004) found that including traditional healers in South Africa in a TB control programme was a worthwhile measure on the basis of the results of this study which showed that traditional healers were not only fully capable of retaining important information about TB but also managed to effectively impart this knowledge to their clients. In post apartheid

South Africa, traditional healers are beginning to be recognised by the government as a 'valuable health resource for the wellbeing of South Africa's people' (Devenish, 2005:257). In an attempt to strengthen traditional healing practices, South Africa's Traditional Health Practitioners Act of 2004 specifically banned unregistered healers from diagnosing or treating terminal illnesses, including HIV/AIDS (Iliffe, 2006). Henderson (2005), found in her qualitative study of two traditional healers in Kwazulu Natal, South Africa, that 'in the face of the HIV/AIDS epidemic, healers are insistent in stating that they have no solution to the disease within their own healing framework' (Henderson, 2005) and thus a collaboration with formal health workers can be viewed as a means of essentially bridging the gap between the two paradigms. The two paradigms can complement one another.

Public Health and Human Rights

Human rights concepts and ideas play a substantial role in public health policy and debates. Traditional public health measures have generally focused on limiting the spread of infectious disease by imposing restrictions (e.g. quarantine or isolation) on the rights of those who are infected or identified as vulnerable to infection (Mann et al, 1999). These measures have been particularly exacerbated when it comes to HIV/AIDS, TB, STI and leprosy control. They can be traced back to the US in the 1920s where health officials debating treatment and preventive measures for STIs proclaimed that 'the progress of preventive medicine has been a history of the conflict between the so called rights of the individual and the higher rights of the community' (Heymann and Sell, 1994: 195).

Public Health and Human Rights the: example of TB:

An important reflection of this conflict is evident in the World Health Organization (WHO) strategy known as Directly Observed Treatment Short Course (DOTS). The aim of DOTS is to tackle the global burden of TB. This strategy entails an approach where, for six months, a patient has to take their medication whilst directly watched by a health worker who carefully monitors their adherence to the drug regimen. DOTS is an example of a health programme that limits the autonomy and rights of the individual patient in the interests of protecting those with whom they come into immediate contact with from contracting TB (Garner and Volmink, 2003).

Conversely a human rights approach to health that prioritises the rights of the individual may do so at the risk of possible adverse effects on the health of the public. In South Africa, patients with Multi Drug Resistant (MDR) TB may sometimes be discharged from hospital because it is viewed by the health authorities that it is a violation of their rights to keep them at a health facility or to isolate them against their will. Their family and individuals with whom they come into contact are then at risk of contracting TB from them. Singh et al (2007) argues that the South African public health system should offer incentives to patients infected with MDR and Extensively Drug Resistant (XDR) TB as a means of motivating them to remain in hospital and to participate in the DOTS process. A human rights approach should indeed ideally balance public health and human rights objectives.

Cultural Rights versus Public Health

The right to cultural identity is in potential conflict with public health objectives as mentioned in the previous chapter. This tension is illustrated briefly in the following examples.

In Nigeria in 2003, the governors of two Islamic states placed a moratorium on polio immunisation claiming that traces of oestrogen and progesterone in the vaccine could cause infertility and possibly even HIV/AIDS in Muslim women. These leaders believed that the polio vaccine was developed as part of a US led plot against Muslims in Nigeria. The actions of these leaders led to a rise in the incidence of polio in this region (Kapp, 2004).

Another cultural practice that highlights this tension between cultural rights and public health objectives is that of female genital mutilation (FGM). FGM is an old practice that entails the ritual cutting of the female genitalia in girls and young women and exists in the Middle East and Africa. FGM has a number of cultural objectives which allude to the preservation of cultural identity, female virginity, sexuality and family honour (Toubia, 1995). There are members of cultural and religious communities such as Muslims and Coptic Christians who strive to maintain this practice. FGM has both adverse long term and short term health consequences (WHO, 2000).

A third example involved two Rastafarian children who were turned away from their school in Cape Town, South Africa. The reason given for this action was a school requirement that the children display clinic cards and immunisation records to the school authorities. However the children's father believed immunisation to be against his cultural beliefs and stated that he

and his family 'had a right to live the way of their ancestors' (Powell, 2006). The parents' exercise of their cultural beliefs led to discrimination against their children because of the health policy applied to school entrants.

Balancing Public Health and Cultural Rights

At the same time the success of many public health programmes are dependent on 'creating trust in the message and the agent' (London, 2002:679) which means successful programmes need to incorporate respect for cultural rights. There are notable HIV/AIDS programmes in South Africa that have integrated cultural ideals or world view into their objectives. For example, HIV/AIDS treatment programmes in Kwa Zulu Natal have successfully incorporated traditional healers (London, 2002).

Gruskin and Tarantola (2002) argue that human rights need not necessarily be the antithesis of public health concepts. A way of ensuring protection of human rights in public health contexts is by applying tools and frameworks that attempt to help create synergy between public health and human rights (Gruskin & Tarantola, 2002). These tools draw on the Siracusa principles which were developed in 1984 by a United Nations panel of experts. These principles are essentially guidelines for when and how limitations of individual human rights could be justified by the general welfare, for example, for public health goals. Public health policy therefore needs to be developed in accordance with the Siracusa principles to avoid potential conflict between human rights and public health ideas. In fact principles of non discrimination and equality can advance the health of the public (Gruskin and Loff, 2002).

Table 1 below summarises the Siracusa principles:

Table 1: Summary of the Siracusa Principles
1) First the proposed restriction has to be provided for and implemented in accordance with the law 2) Second the restriction has to be directed towards a legitimate objective of general interest, such as preventing further transmission of the HI Virus 3) Third, it must be strictly necessary to achieve the objective in question 4) Fourth, no less intrusive and restrictive means should be available to reach this objective 5) Fifth, it cannot be unreasonable or discriminatory in its application The burden of proof falls on those who want to restrict rights, and concrete public health evidence is needed to genuinely respond to the last three criteria.

(Source: United Nations, 1984)

Mann and Gostin's tool of analysis (1999) is based on the Siracusa principles and looks at key elements of public health policies (Table 2). Firstly, the public health objective and its feasibility are determined. Thereafter the framework considers whether or not the policy protects human rights. The policy's ability to address equity and fairness is also considered. It is also crucial that the components of the policy and the direction they will eventually take are supported by epidemiological research evidence. The framework eventually considers means of creating synergy between protection of human rights as well as public health objectives (Mann & Gostin, 1999).

Table 2: Summary of Mann and Gostin Tool of Policy Analysis (1999):
Step 1: Clarify the public health purpose Step 2: Evaluate likely policy effectiveness Step 3: Determine whether the public health policy is well targeted? Step 4: Examine the policy for possible human rights burdens Step 5: Determine whether the policy is the least restrictive alternative that can achieve the public health objective. Step 6: If a coercive public health measure is truly the most effective, least restrictive alternative, base it on the significant risk standard. Step 7: If a coercive measure is truly necessary to avert a significant risk, guarantee fair procedures to persons affected.

Source: Mann et al (1999).

This model is applied in Chapter 6 to the question of an appropriate policy of incorporating traditional healing in ARV treatment programmes.

Conclusion of the Literature Review and Motivation for the Study

The literature review shows that literature about alternative healing strategies for HIV/AIDS patients in South Africa is sparse. Though there is literature about previous collaborations between medical doctors and traditional healers, there are few studies that have probed the experiences of either of these parties with regard to HIV/AIDS care or their views and conditions for collaboration. There is also little or no information with regard to suggestions for a ARV treatment policy that respects cultural rights and public health objectives. Thus there is a great need for this study.

CHAPTER 3: Methodology

3.1) Introduction

The study was conducted during 2005 and 2006 at health facilities and homes of traditional healers in six townships near Cape Town. In South Africa, the term 'township' refers to urban areas created during the apartheid era, as areas of single race residential developments which confined people who were not white (Africans, coloureds and Indians) to areas designated for their specific racial group.

The townships where this study was conducted were Khayelitsha, Delft, Langa, Gugulethu, Hout Bay and Du Noon. The health worker study was conducted in facilities in Khayelitsha, Hout Bay and in Groote Schuur hospital while the traditional healers were interviewed in Gugulethu, Langa and Delft. Table 3 on the next page displays some basic demographic information about the areas where the study was conducted.

Table 3: Socio Demographic Information of Areas where Study was conducted

Area	Percentage household earning < 192 000 per annum	SES Index[1]	Households living in informal dwellings
Khayelitsha (formal)	78.83	59.62	2.48
Khayelitsha (informal)	83.34	66.29	91.95
Delft	N/A	N/A	N/A
Hout Bay	N/A	N/A	N/A
Langa (formal)	65.75	55.29	35.97
Langa (informal)	N/A	N/A	N/A
Gugulethu (formal)	50.40	51.24	10.33
Gugulethu (informal)	84.19	50.24	67.87
Du Noon (formal)	78.23	64.04	4.74
Du Noon (informal)	N/A	N/A	85.11

Source: Information and Knowledge Management Department Strategic Information Branch, City of Cape Town, March 2006 in (Gie, 2007)

Health Facilities

Hout Bay Main Road Clinic has about 480 patients on ARV treatment while Khayelitsha Site B has approximately 2369 patients on ARV treatment. Groote Schuur Hospital, a tertiary referral hospital close to the Central Business District of Cape Town has an ARV treatment programme that provides approximately 640 patients with their medication (Osler and White, 2007).

The patients were interviewed in the Gugulethu and Du Noon townships. The clinics where they were interviewed are called the Hannan Crusaid clinic situated in the Gugulethu township and the Du Noon clinic situated in the Du Noon township.

[1] SES Index is a combination of four indicators (% of households earning less than 192 000 per annum, % of adults of over 20 years with highest educational level less than matric, % of the economically active population that was unemployed, % of the labour force employed in elementary or unskilled occupations).

The Hannan Crusaid ARV Treatment Centre is funded by The Desmond Tutu HIV/AIDS centre (DTHC). DTHC is part of the Institute of Infectious Diseases and Molecular Medicine at the University of Cape Town. The centre funds ARV treatment for public sector patients mostly from the Nyanga district (Bekker, 2005) and also runs a clinical trials unit. The clinic had screened more than 800 potential ARV candidates by 2005. During the same year, the clinic reported a viral suppression rate of about 87% for patients who had been on treatment for more than a year. The clinic also runs a community based project in the Gugulethu area called 'Sizophila' or 'We will survive'. This project is a specialised adherence intervention and has trained a group of 24 counsellors, many of who are HIV positive themselves in education and support initiatives for patients who are commencing treatment (Bekker, 2005).

The clinic at Du Noon is run by the City of Cape Town health services and consists of a number of health services in addition to its ARV programme. The services include TB prophylactic and treatment services, treatment of sexually transmitted infections and reproductive health care. The clinic's ARV programme consists of about 600 patients on ARV treatment (including adults and children) (personal communication with Mrs M Osler and Ms C White, Provincial Department of Health, Cape Town).

Study Design

Each sub study design is described below:

3.3.1) Health Worker sub study

This was a qualitative study involving in-depth one-on-one interviews and focus groups with health care workers (doctors, nurses, ARV counsellors and patient advocates) working in

public sector facilities that provide ARV treatment. Interviews were conducted in primary and tertiary level facilities in Khayelitsha, Observatory and Hout Bay in Cape Town. An interview guide (Appendix 1) was used to facilitate the interview process along with informed consent procedures. Two additional focus groups were conducted, one at each facility at the Gugulethu and the Du Noon clinics with patient advocates and ARV counsellors.

3.3.2) Traditional Healers sub study:

This sub study was a qualitative study involved in-depth one-on-one interviews with traditional healers from Langa, Gugulethu and Delft townships.

3.3.3) Patient sub Study

Both quantitative and qualitative methodologies were employed to interview patients who access ARV services (i.e. patients who are on treatment and patients who are awaiting treatment) at the Gugulethu and Du Noon clinics. The quantitative arm of the sub study collected demographic and treatment information about patients and was run as a cross sectional study based on a standardised questionnaire administered to patients who were about to start or were already on ARV treatment. The qualitative study was based on a sub sample of patients who admitted to the use of traditional medicine. The results of the two studies complemented one another.

3.4) *Population and Sample*

3.4.1) Health Worker sub Study:

The population of interest was that of care givers working in ARV facilities at Khayelitsha, Groote Schuur Hospital and Hout Bay Clinic. 10 health workers were purposively recruited for in depth interviews. The criterion for recruitment was having self identified experience of working in ARV treatment facilities. The sample comprised one senior nursing sister, six doctors, one pharmacy assistant and two ARV counsellors.

The two focus groups (one at each facility i.e. Gugulethu and Du Noon) comprised patient advocates and ARV counsellors. The Du Noon clinic has patient advocates and one counsellor assisting in the ARV roll out programme. The patient advocates and the counsellor at the Du Noon clinic fulfil similar functions. The Du Noon focus group consisted of four patient advocates and one ARV counsellor. The Gugulethu focus group consisted only of ARV counsellors.

Patient advocates are community based health workers employed at clinics funded by the Non Governmental Organization Absolute Return for Kids (ARK). Their job includes a range of duties. They ensure that patients know when to visit the clinic, guide the patients through the services and support the clinic staff with education and counselling. Patient advocates visit the patients in their homes and answer the questions of both the patients and their families. Many patient advocates are HIV positive themselves and take ARV treatment.

The Hannan Crusaid ARV Treatment Centre in Gugulethu has ARV counsellors assisting in the ARV roll out process. ARV counsellors are involved in the Voluntary Counselling and

Testing processes at the clinics. They conduct counselling sessions with clients prior to their HIV tests. They are required to have reached Grade 11 or matriculation level of high school (i.e. the final two years of high school). Like patient advocates they also conduct intensive home visits and adherence checks. The counsellors conduct classes on Saturday mornings at Hannan Crusaid which are compulsory for ARV candidates to attend. The purpose of these classes is to educate patients about adherence to ARV treatment, opportunistic infections, side effects of ARV therapy and the potential adverse interactions between traditional medicine and ARV treatment.

The patient advocates and counsellors were sampled conveniently after they were identified by the researcher as a potential source of valuable information for this study. Counsellors and patient advocates were included in the focus group, according to their availability at the clinic on the days that the focus group was conducted.

3.4.2) Traditional Healer sub study

The population of interest were traditional healers working in the Western Cape. A sample of ten traditional healers was sought. Recruitment was conducted through a combination of purposive and snowball sampling. Four of the traditional healers were recruited through Dr Joanne Wreford, a social anthropologist affiliated with the Centre for Social Science Research who is also a practising traditional healer. Dr Wreford works for a Non Governmental Organization (NGO) called HOPE which is based at Tygerberg Hospital in Cape Town. This NGO trains traditional healers in HIV/AIDS care and encourages collaboration between traditional healers and the public health sector. The remainder of the sample were recruited with the assistance of an ARV doctor, Dr Carol Cragg, who had

previously worked with traditional healers in Prevention of Mother to Child Transmission of HIV/AIDS interventions. It was challenging to recruit the intended full sample of ten traditional healers. Half the sample did not fulfil the scheduled appointment times due to forgetfulness, indifference or migration to the Eastern Cape province of South Africa. Eventually only five traditional healers were interviewed although ten had been the original sample size sought. The five traditional healers who participated in the study imparted sufficient information and insight into the complexity of the intersection between traditional healing and HIV/AIDS care to justify their inclusion in the study. The researcher was advised by the head of the CSSR to seek no further subjects, given that there were difficulties in recruitment and there was convergence in the findings from the five respondents.

3.4.3) Patient sub Study:

The population of interest for this study was all patients attending the Gugulethu and Du Noon ARV programmes between November 2006 and February 2007. A sample of 90 patients was sought. They we recruited from the waiting area of the clinics through convenience sampling by clinic staff. The sample size was decided by the CSSR on the grounds of feasibility. Two thirds of the sample was recruited at Gugulethu and one third at Du Noon more or less in proportion to the size of the ARV treatment programmes at each of the sites. Although the sample was not representative it was sufficient to elicit both qualitative and preliminary quantitative data.

However, as recruitment proceeded, it was evident that few of the patients were admitting to accessing a traditional healing service or to the use of traditional medicine before or during ARV treatment. At the point where the sample size had reached 80 patients, it was decided to purposively recruit patients who were known (by the counsellors and the patient advocates)

to have accessed a traditional healing service within the last year. The last ten patients were thus recruited on the basis of using traditional medicine. This also enabled a sufficient number (i.e. ten patients) for in depth interviews.

3.5) *Community Access*

Visits were undertaken to the Gugulethu and Du Noon clinics prior to the data collection process. This enabled the creation of a rapport between the researcher and the clinic staff to facilitate the data collection process.

3.6) *Measurement*

The interview guides used in the health workers sub study, the traditional healers study and the focus groups consisted of a set of open ended questions to act as prompts (see appendices 1 and 2). The interview guides explored experiences of the health workers and traditional healers of patients or clients who use ARV treatment and traditional medicine, the problems this has entailed and the advice they give their clients or patients.

The quantitative questionnaire used in the patient sub study drew mainly on questions on sexual and reproductive health from a standard quantitative questionnaire used previously in CSSR surveys in 2004 and 2006 (Nattrass, 2005 b). It was not feasible to use the full CSSR questionnaire in this sub study due to time constraints (the length of the interview recommended by the human subjects ethics committee was 45 minutes to 1 hour including time for translation) so the instrument was shortened. The 'contracted' questionnaire (Appendix 3) contained questions about patient demographics and traditional healing as well as questions about ARV adherence, knowledge, positive effects of the treatment on the lives of the respondents and side effects. These questions were closed ended (yes or no to the

majority of the questions). In the case of the questions about adherence, knowledge and side effects, the respondents were given structured options. With regard to the former, the respondents answered never, sometimes or often to a question about how many times they had missed taking their ARV pills in the last three months. The question about side effects gave options that were examples of common side effects in ARV patients. The respondents were asked to state closed options of the positive effects that ARV treatment had had on their lives. With regard to knowledge of ARV treatment, they were asked question about ARV treatment and asked to state whether they are true or false.

The questions relating to traditional healing begin with a question that was worded: 'have you seen a traditional healer or a sangoma in the last year' followed by questions on how many visits the respondent had made to the traditional healer in the last year, what the illness or problem was for which advice was sought, what the consultation entailed (i.e. diagnosis made and treatment regimen) and whether or not the treatment given by the traditional healer helped the respondent or not. These were all closed ended questions with structured options.

The researcher amended sections of the 'contracted' questionnaire and added a few open ended questions about the use of traditional medicine (see appendix 3). This allowed for some extraction of qualitative data (through quotes and narratives) from the larger sample. Another important technique employed by the interviewer was an additional question at the end of the questionnaire. If the respondents answered that they had not seen a traditional healer or a sangoma in the last year, they were asked the reasons for this at the end of the interview. This measure (which was not an in depth interview but instead one open ended question) extracted additional qualitative data as many patients responded with a narrative of

their previous visits to a traditional healer. These quotes were copied down by the researcher verbatim (i.e. they were not recorded).

The patients in the purposive sub sample of ten who were known to be accessing traditional healers answered the quantitative questionnaire and then were followed up and interviewed using a set of open ended qualitative questions relating to traditional healers and traditional medicine (see appendix 4). This was an in depth interview. These interviews were recorded and transcribed.

3.6.1) *Translation*

The health worker sub study was conducted in English. The traditional healer study was conducted in English and Xhosa partly with the help of the CSSR translator, Ms Nondumiso Hlwele. Ms Hlwele was familiar with the interview guide. The researcher met with Ms Hlwele to discuss the interview guides before conducting the interview.

The patient questionnaire and in depth interview guide were administered by the researcher. Ms Hlwele assisted with Xhosa translations and was also familiar with the patient questionnaire as she had translated in the previous CSSR studies.

The translation was transcribed verbatim from the tapes. Table 4 on the following page is a summary of the methodology used in the three sub studies.

Table 4: Summary of the Methodology of the three sub studies

Sub Study	Participants	Methodology of Data Collection
Health Workers	10 Health care workers (nurses, doctors, ARV counsellors) working in ARV care. 2 focus groups with patient advocates and ARV counsellors	Qualitative in depth one on one interviews Focus group discussions
Traditional Healers	5 traditional healers working in HIV/AIDS prevention organization in Cape Town	Qualitative in depth one on one interviews
HIV positive patients	90 patients	Cross sectional study (n= 90) In depth interviews with patients who admitted to using traditional medicine (n=10)

3.7) *Data Management and Analysis*

Quantitative Data

The quantitative data was captured from the questionnaires at the CSSR into a Microsoft Excel database. Data capture was assisted by Ms Celeste Coetzee, a doctoral candidate, based at the CSSR. As the measuring instrument had been used in previous CSSR studies, a template for the database was available and the majority of the data could be captured from the questionnaires. The variables religion, age, education, gender, employment status and treatment status (i.e. whether the patient is about to start ARV treatment or is currently on ARV treatment) were created. The variables religion and treatment status were not used in the final analysis. There were only three patients in the final sample who had not begun ARV treatment so it was not worth comparing on treatment status. With regard to religion, too many options were given by respondents for meaningful comparison.

The data were cleaned. The variables side effects and adherence were re coded as there were too many options. Education was recoded as number of years passed at school. The data

were exported into STATA. Questions which were not answered were treated as 'missing' variables in STATA.

Univariate analysis was done first to describe the data.

Secondly bivariate analysis was conducted which entailed the testing of independent variables against whether or not the respondent had visited a traditional healer in the past year. The hypothesis was tested of an association between visiting a traditional healer in the last year and the variables age (years), gender (% female), level of education (years passed at school), employment status (% unemployed), side effects experienced from ARV treatment, knowledge of ARV treatment (% reporting whether or not statements about ARV treatment are true or false), positive effects of ARV treatment (% reporting positive effects of ARV treatment), adherence to ARV treatment (% reporting they never or rarely missed tablets in the past three days), visits made to a herbalist in the last year and visits made to a spiritual healer. For adherence, the respondents were asked if they had missed taking their ARV treatment in the last month and if so were prompted for what reason (e.g. forgetfulness, being away from home etc). They were then asked to rate their adherence in the last month. The variable positive effects of ARV treatment was based on naming positive effects ARV treatment on their lives (e.g. sleeping better, contracting less opportunistic infections).

The Chi Squared Test of association was used in the analysis to test the presence of associations between categorical variables and reported visits to a traditional healer within the last year. Statistical significance was set at $p < 0.05$. A t test was used for testing the association between age and visits made to a traditional healer.

Qualitative Data:

The qualitative data from all three sub studies was analysed by means of a thematic analysis whereby similar themes are identified across the transcriptions of all the interviews.

With regard to qualitative data from the patient sub-study the respondents were divided into three groups for analysis: those who had never accessed a traditional healer, those who had accessed a traditional healer prior to the interview or prior to starting ARV treatment and those who are actively crossing between the two systems of healing (i.e. concurrent usage of ARV treatment and traditional healing paradigms at the time of interview).

These themes are presented and discussed in the results and discussion sections of the thesis.

3.8) *Ethical Considerations*

Ethical approval was obtained for the study from the UCT Human Ethics Committee (REC Number: 376/2006).

Informed consent (delivered by the interviewer and translated into Xhosa by the interpreter for Xhosa speaking respondents) was obtained from all the participants in the study. The informed consent procedure entailed informing the participant what the study was, what would happen with the results, potential harms and benefits, that their participation in the study was completely voluntary and that they could stop at any time during the interview. They were also assured of confidentiality (i.e. that their names will not be used in the written report and that information will not be disclosed to a third party without their permission).

The questionnaire was anonymous (i.e. with no identifying data).

Each participant received compensation in the form of a R50 food voucher. The participants were advised by the interviewer to conceal the voucher from other patients in the clinic. This advice was given in the interests of their safety.

After the interviews the questionnaires were kept secure (i.e. locked) and not disclosed to a third party.

Feedback of the results was delivered to relevant stakeholders associated with the research sites. In the case of Du Noon, the results were delivered to the City of Cape Town health services. In the case of the Hannan Crusaid Clinic, feedback was delivered to the director of the Desmond Tutu HIV/AIDS Centre.

The results will be made publicly available at the CSSR. Future and current CSSR research projects will have access to the anonymous data. The results of the thesis are made available by means of the CSSR website. The results will appear in the form of an article or 'working paper'.

CHAPTER 4: RESULTS

4.1) Attitudes of Health Care Professionals in South Africa to the use of traditional healing paradigms by HIV Positive Patients.

Introduction

This section describes the findings of the exploratory qualitative study of ten health care professionals (doctors, nurses and treatment support counsellors) working in ARV treatment roll out sites in two informal settlement clinics and a tertiary referral hospital in Cape Town. This sub study probed their experience of patients using traditional medicine (and the problems this has entailed), the advice the health professionals give their patients about taking traditional medicine, and their attitudes towards possible collaborations with traditional healers. Table 5 on page 47 summarises basic demographic information of health workers interviewed.

4.1.2) Findings

Most of the health workers suspected that their ARV patients were consulting traditional healers. About half of the health workers were certain that some of their patients were consulting traditional healers. The others suspected that their patients were using traditional medicine but were not certain.

Evidence

The health workers were asked to discuss evidence to support their belief that their patients were using traditional medicine. This evidence appeared to be based on patient signs and symptoms or on what the patients had told them.

> Scarring, jaundice and unusual rashes are a sign that I have learnt to regard as proof that patients are indeed using traditional medicine (ARV doctor).
>
> Evidence that patients are using traditional medicine include symptoms of vomiting, diarrhoea and dehydration (Nursing sister).
>
> Patients have told me that sangomas give them bottled fluid but they refuse to tell me what is in the bottles (ARV doctor).

There was no consistency in evidence employed by health workers as proof that their patients are using traditional medicine or visiting traditional healers.

Treatment Advised by Traditional Healers for HIV Infection

When asked about what patients reported as being the diagnosis by traditional healers of their illness, most of the health care professionals cited witchcraft (either directly or indirectly through reference to jealousy and poisoning) as the ultimate cause of illness. This led to discussion about what treatment strategies the health workers had heard traditional healers employed for their HIV positive clients. The health workers had heard of various treatment strategies. In particular, the health workers had heard of two rituals prescribed by traditional healers to cure HIV infection:

> HIV positive patients are advised by sangomas to slaughter cows in order to treat HIV infection (Nursing sister).
>
> A patient came to me and told me that she had been told to steam out her vagina to get rid of the HIV infection (ARV counsellor).

Treatment of Opportunistic Infections by Traditional Healers

The health care professionals were asked about their experience of patients being treated for AIDS related opportunistic infections by traditional healers. Most said they had experienced patients being treated for opportunistic infections (including tuberculosis) by cleansing through purging- i.e. 'instigating vomiting or diarrhoea (sometimes both), with an emphasis on vomiting'(Nattrass, 2005 (b): 64)

Concerns of health workers about potential harm of traditional healing practices

On the whole the health care professionals were concerned about the potential of traditional healers to cause harm at both a social level and an individual patient level. For example, seven out of ten health workers believed that the view that sexual intercourse with a virgin could cure HIV came from traditional healers. Another concern was that patient uncertainty and choice of traditional healing may result in delayed treatment with poorer prognosis:

> I have witnessed TB patients who experience internal conflict when making decisions about whether to use traditional medicine or biomedical TB treatment. Many TB patients delay seeking treatment at the clinic because they wish to consult traditional healers first. During the process of seeking and using traditional medicine, patients can lose trust in traditional healing systems. However they only adhere effectively to a biomedical drug regimen when the traditional resources become exhausted and can no longer help them (ARV doctor).

Another health worker pointed to the problems of interaction between traditional medicine and ARV drugs. One of the doctors attributed the death of a patient to sangoma prescribed medication the patient had taken:

> I had a patient who developed Steven Johnson syndrome which is a life threatening condition. When a patient has this disease, even the mildest of drugs (e.g. pan ado) could result in adverse, critical liver reaction. This patient consulted a sangoma who provided a herbal remedy that was too strong. The patient died (ARV doctor).

Another respondent spoke more specifically about drug interactions:

> There is another potential problem (of using traditional medicine while taking ARV treatment) This is the issue of adverse drug interactions. Traditional medicine can inhibit metabolism or induce it. If metabolism is inhibited, the toxicity of ARV drugs could be increased (Specialist pharmacologist).

One doctor went so far as to refer to his experience of working in primary health care clinics in Angola and Mozambique to explain concerns about the potential harm of traditional healing practices:

> When I worked in Angola and Mozambique, I was involved in programmes to discourage traditional healers from using the same blade on many patients for blood letting. This could cause HIV to spread we told them.

Health workers were thus consistently concerned about potential harms to patients from traditional medicine usage.

Strategies to deal with traditional medicine

Strategies emerged from the experiences of these health workers in dealing with the issue of traditional medicine directly. One doctor spoke of efforts to identify patients who may have been secretly using traditional medicine when on ARV treatment.

> We were so concerned about this potential conflict between ARV treatment and traditional medicine we asked our counsellors to administer a questionnaire to patients in order to find out if they were using traditional medicine. Thereafter the ARV team has not only tried to communicate openly with patients about traditional medicine but also focused some research interest on finding out more about the properties of traditional drugs and also about the interaction between traditional medicine and ARV treatment (Senior Pharmacologist).

Two doctors spoke of adopting a contract with their patients that included openness about alternative treatment strategies. One of the doctors adopted a written contract with her patients and another what he calls a 'faith based contract.' This method helps create a safe, space for doctors and patients to discuss healing strategies. As one of the doctors put it:

> I am pro choice (with regard to the use of traditional medicine). Pro informed choice. There are certain traditional drugs that have bad interactions with ARV treatment and I try to explain this to my patients in the form of what I call a 'trust based contract.' I once had a patient who after 6 months on ARVs vomited profusely. The ARV treatment was not working and of course this is highly unusual. The reason for this failure of ARV treatment was due to use of traditional medicine. She saw this failure and subsequently adhered strictly to her ARV regimen. She and other patients like her will never be denied ARV treatment when they ask for it.

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Another clinician stressed the importance of sensitive language:

> All my patients enter into a contract with me before commencing ARV/TB treatment. Basically this entails them telling the truth about any of the medication they are on (not only traditional medication). I use sensitive language when communicating with my patients. If they wish to see a sangoma before commencing ARV/TB treatment I say 'that's fine'.

The issue of trust was a common theme in this particular sub study. The doctors' responses illustrated the importance of trust in the ARV treatment process.

Collaborative Efforts between health care workers and traditional healers

Interestingly, two of the doctors interviewed had been involved in attempts to form collaborative or consultative relationships with traditional healers. One of them had participated in a formal TB diagnostic programme in which sangomas had been included. Another said that he had held numerous meetings with sangomas in informal settlements close to Cape Town to discuss the treatment of sexually transmitted infections:

> The sangomas I have worked with are very guarded with regard to their traditions and treatment strategies they are using to treat these (sexually transmitted infections).If a culture of mutual trust is built, there may be more sharing of knowledge and information between sangomas and health care professionals (ARV doctor).

When asked about the potential for developing collaborative partnerships with traditional healers most health care professionals were cautiously in favour. For some this was a necessity forced on them by circumstances. At best health care professionals offered conditional support for collaborating with traditional healers; conditional on the traditional healer being trained to support the (primary) biomedical intervention:

> Yes (I feel that sangomas would be a welcome addition) with training and information. Sangomas need to realise that religion ends at one point and science begins at another (ARV counsellor).

> I would rather work with sangomas to prevent them from perceiving us (clinicians) as a threat. Another reason that I would rather work with them is to avoid the possibility that they may advise patients not to adhere to ARV treatment regimens (Senior Pharmacologist).

There were two dissenting voices with regard to the partnership issue. One was a doctor working part time in the Khayelitsha clinic in Cape Town. She argued that a partnership between medical doctors and traditional healers was not a feasible idea considering the vast differences between the strategies of medical doctors and traditional healers. She said that she did not 'agree with traditional medicine at all'. Similarly an ARV counsellor expressed concerns about traditional medicine:

> Traditional medicine is simply too strong for HIV positive patients. Traditional drugs cause vomiting and diarrhoea. This is too unpleasant an experience for an ARV patient to undergo.

The role of the HIV Positive Sangoma

One of the most interesting issues to emerge from this study is that some of the health workers (of which two are doctors) had some experience of treating HIV positive sangomas. According to the senior nursing sister and a treatment counsellor, this had a positive impact on the treatment programme (albeit potentially at the cost of the credibility of the sangomas):

> When HIV positive sangomas access ARV treatment at the clinic, people realise that sangomas do not have the cure for HIV/AIDS. When they see this, the community feel encouraged to make use of the clinic's voluntary counselling and testing services as well as ARV treatment.

> We have a number of sangomas on ARV treatment at the clinic. I think it is important for sangomas to be trained in the area of biomedicine and for us clinicians to work with them and not against them. Their training is very different from ours. I think they would be most useful in the more social areas of disease and conflict resolution. They can have a psychotherapeutic function and work in home based care. But their training must be homogenised (standardised). I would be even keener to work alongside sangomas who are on ARV treatment as this is closer to a classical health system and a good referral point (ARV doctor).

One of the doctors was more sceptical. He felt that the impact these sangomas could make on their community was largely influenced by whether or not they chose to disclose their HIV status. Secondly, he was weary of the 'rogues' who would gladly

access ARV treatment for themselves but still advise others to take traditional medicine.

The role of the HIV positive sangoma in ARV care could be either positive or negative depending on a range of conditions. Amongst these are disclosure of HIV status to their clients.

Overview of Findings

This study reveals that health workers involved in the ARV treatment roll out are concerned about the possible adverse impact of the use of traditional medicine on the effectiveness of their biomedical treatment regimens. Their concerns emanate from their experience of toxic interactions and from evidence that traditional medicine may undermine adherence to treatment regimens or undermine its effectiveness as a consequence of purging strategies prescribed by the traditional healers. Most of these health workers recognise that their patients will continue to use traditional medicine and thus it is preferable to create a treatment context in which patients can discuss their treatment strategies openly with the doctor. Most of them are also open to the idea of collaborating with traditional healers- although this is inevitably qualified by the requirement that the traditional healers be properly trained, and that their role is to support the biomedical roll out. It is clear that the health workers thought that collaborative relationships with traditional healers are useful in the areas of adherence, psycho social counselling, referral and home based care. The health workers also thought that traditional healers should not prescribe dangerous, strong substances to HIV positive patients.

At most, the health care professionals concede that traditional healers are important culturally, spiritually and psychologically. If there are to be collaborations between traditional healers and health workers, these doctors advocate a clear hierarchy with the

biomedical intervention having clear priority. What this would mean in practice, is that untested herbal remedies should be avoided by people on ARV treatment and that traditional healers should concentrate on purely spiritual treatment as rituals. Few health workers recruited into this sub study did not really recognise the rights of patients to choice of healing strategy.

Table 5: Summary of Socio Demographic Information of Health Workers

Category of Health Worker	Location	Years working in this position	Gender	Key Attitudes
Doctor	Khayelitsha Clinic	4	Male	In favour of a partnership in the area of diagnosis
Doctor	Khayelitsha Clinic	4	Male	In favour of a partnership especially in psycho social work and home based care
Doctor	Khayelitsha Clinic	2	Female	Not in favour of a partnership
Doctor	Hout Bay Clinic	7	Female	In favour of a partnership in treatment adherence
Doctor	Groote Schuur Hospital	20	Male	In favour of a partnership in ARV roll out, TB diagnosis
Doctor	Groote Schuur Hospital	10	Male	In favour of a partnership in ARV treatment
Nursing Sister	Khayelitsha Clinic	5	Female	In favour of a partnership; VCT and adherence
ARV Counsellor	Khayelitsha Clinic	2	Female	In favour of a partnership
ARV Counsellor	Khayelitsha Clinic	2	Female	In favour of a partnership
Pharmacy Assistant	Khayelithsha Clinic	4	Female	Uncertain of a partnership

4.2 Attitudes of ARV Counsellors and Patient Advocates in South Africa to the use of traditional healing paradigms by HIV Positive Patients.

Focus Groups

4.2.1) Introduction

The first focus group was conducted with the ARV counsellors at the Hannan Crusaid Antiretroviral Treatment Centre, Gugulethu and the second with the patient advocates and one counsellor at the Du Noon clinic. The focus group participants were asked to speak about their experiences of patients using traditional medicine, the advice they give these patients and their opinions of traditional healing practices. The demographic information of focus group participants is summarised in Table 5.

4.2.2 Results

The focus group participants discussed issues relating to traditional healing and HIV/AIDS freely. They spoke of the rumours they have heard of HIV positive children being treated with traditional medicine by their parents or elderly care givers. They were of the opinion that HIV positive people who visit traditional healers are likely to be unaware of ARV treatment. Interestingly, one patient advocate said that visits to a traditional healer could result in an unwillingness to disclose HIV status. Another patient advocate said that she had counselled patients who had been 'abusive' towards the clinic staff when the topic of traditional medicine was broached. When advised not to use traditional medicine concurrently with ARV treatment, these patients reacted by swearing at the clinic staff and refused to discuss the issue. Overall, it appeared that the ARV counsellors expressed negative attitudes towards traditional healing practices.

Potential harm of Traditional Healing Practices to HIV positive people

The ARV counsellors feel that traditional healing practices pose potential harm to HIV positive patients whose immune systems are already compromised.

> There are traditional healers who insert spades into patient anuses. They prescribe traditional medication that makes the patients vomit profusely. I worry that they will harm HIV positive patients especially because they induce diarrhoea which is bad for HIV positive patients (ARV Counsellor, Focus Group).

> Traditional practices are harmful to HIV positive people especially because of the usage of the same blade. Traditional healers send out messages that they have the cure for HIV/AIDS.

Evidence of the use of Traditional Medicine by ARV Patients

Although the focus group participants did not necessarily have scientific evidence that their patients were using traditional medicine, some of them suspected their clients were accessing a traditional healing service:

> I do not have scientific evidence that my patients are taking traditional medicine but I have had the experience of patients on Highly Active Antiretroviral Treatment (HAART) wanting to stop their ARV s and take traditional medicine. They tell me their concerns. We have a trust based relationship.

> I have counselled three clients who were mixing traditional medicine and ARV treatment. All my clients are close to me. They told me what they were doing. I had noticed they were nauseous and vomiting all the time. I asked them why and they said they were using traditional medicine while on HAART.

Generally, the focus group participants suspected use of traditional medicine in patients who bear visible 'body scarring' and who have had their little finger amputated.

> I think they (the patients) are lying to you (the researcher) when they say they don't use traditional medicine. They have scars and no little finger. This means they are seeing traditional healers all the time.

Choice of treatment strategy was an important theme that emanated from the focus group discussions.

Affiliation of Patients to Traditional Healing

Some of the focus group participants were so concerned about the potential inclination of their patients towards the traditional healing paradigm, they advised the patients of the possible adverse interactions between ARV treatment and traditional medicine:

> I don't know that much about the consequences of traditional medicine so I explain to the patients my understanding is that ARV drugs and traditional medicine do not mix well. I have a pro choice attitude but I advise the patients to decide early about whether to take HAART or traditional medicine.
>
> I tell the patients that if you decide on traditional medicine, then don't take ARVs. I am pro choice when I advise the patients but I stress that the interactions between traditional medicine and ARV treatment are very bad for the body...

It seemed that despite these concerns, respecting patients' rights to choose a treatment strategy was prominent in the approach of the participants to their clients.

The Role of the HIV Positive Sangoma

The issue of the HIV positive sangoma emerged in the focus group discussions. Two participants had had contrasting experiences of counselling HIV positive sangomas. As the first participant explained:

> Yes, (I have had experiences of treating) traditional healers in training. I am not sure that they even mention that they are on ARVs to their clients or friends. They are so steeped in the traditional healing profession that they only help themselves

The second participant expressed more positive views about the role of the HIV positive sangoma in the ARV roll out procedure.

> I have seen HIV positive traditional healers at the clinics. I know they are HIV positive because they have the beads and white substance smeared all over their faces. I think they have a good influence over their clients who are HIV positive as well. Some of them come (here to the clinic) very ill and after taking their ARVs properly, make a miraculous recovery. This has to have a good, positive influence on other HIV positive people in the community.

One of the participants said she had counselled a number of patients who expressed a desire to abandon their ARV regimen in favour of their 'sangoma initiation process'.

Migration from the Eastern Cape appeared to be a significant factor influencing potential use of traditional medicine. This region is of great spiritual significance to traditional healers and patients who migrate from there may well be exposed to traditional healing practices:

> There are patients who are mixing ARV treatment and the medication they get from the sangoma. Many of them have come from the Eastern Cape. We talk to them to try to explain that ARV treatment is the best for them. Sometimes they listen. Sometimes they don't listen. But we don't give up easily.

One of the participants raised the issue that the traditional healing paradigm is not always capable of dealing with HIV/AIDS and its associated issues. He told an interesting story that illustrated the idea that patients mix paradigms:

> I knew an epileptic patient who was dissatisfied with his epilepsy medication that was given to him at Somerset hospital. This patient consulted a traditional healer and was satisfied with his session. However when he was diagnosed as HIV positive, he took ARV treatment without a fuss. He proceeded to use traditional medicine for his epilepsy.

Confusion

Participants had experienced patients confusing HIV/AIDS and TB treatment. This confusion impacts of choice of healing strategy. The traditional view of the aetiology of TB is often different to that of HIV/AIDS. TB is an older illness than HIV/AIDS and thus people suffering from TB do tend to seek traditional advice.

Two of the participants said they had paid home visits to HIV positive patients who have also been diagnosed with TB. These patients believe that TB is caused by poison. Thus they visit a traditional healer for TB treatment. At the same time they receive TB treatment at the clinic.

The clinic employs the Directly Observed Treatment Short Course (DOTS) TB treatment process. This treatment strategy ensures adherence to TB treatment. According to the patient advocates there are no known adverse interactions between TB treatment and traditional medicine. Thus when the patients begin to feel better, they believe that it is the traditional medication that is responsible for an improved health status.

> I have had some HIV positive patients who also test positive for TB. They visit traditional healers for different reasons. The TB treatment they take makes them feel better and they become confused. They think that the traditional medicine that the traditional healer is giving them is what is making them feel better. Sometimes because this, they want to stop taking ARV drugs.

> I had a patient who visited a sangoma for help. He was HIV positive and also needed TB treatment. The sangoma told him not to take his ARV treatment. He listened to the sangoma. I think that the TB treatment was making him feel better but he thought that the sangoma was able to cure his TB and his HIV. He was not allowed to continue his ARV treatment until he promised that he would not take traditional medicine.

4.2.3) Overview of Findings

These focus group discussions show that patient advocates and ARV counsellors support an ARV roll out procedure as well as adherence interventions. They have counselled patients who are confused about TB medication, who wish to become sangomas and who have delayed accessing ARV treatment while taking traditional medicine. They are concerned about possible adverse interactions between traditional medication and ARV treatment. They are also reluctant to collaborate with traditional healers as they feel that they (the traditional healers) are not willing to adapt their beliefs to the procedures that the clinic has implemented to ensure effective ARV roll out and adherence interventions.

Table 6: Summary of Socio Demographic Information of Focus Group Participants

Study ID Number	Gender	Counsellor/Patient Advocate	Clinic
1	M	Counsellor	Gugulethu
2	F	Counsellor	Gugulethu
3	F	Counsellor	Gugulethu
4	F	Counsellor	Gugulethu
5	F	Counsellor	Gugulethu
6	M	Patient Advocate	Du Noon
7	F	Patient Advocate	Du Noon
8	F	ARV Counsellor	Du Noon
9	F	Patient Advocate	Du Noon
10	F	Patient Advocate	Du Noon

4.3 Attitudes of Traditional Healers in South Africa to their Clients on ARV Treatment

4.3.1) Introduction

This section presents results from the qualitative study of five female traditional healers. These traditional healers were working for HIV/AIDS affiliated organizations in Cape Town and were given pseudonyms for this report and will be referred in the text as Thandi, Xholiswa, Flora, Nandi and Lulu. The study investigated and documented the attitudes of these traditional healers to their HIV positive clients, the advice they give these clients, their perceptions of the role of HIV positive traditional healers in the fight against HIV/AIDS and their attitudes towards working with formal health care workers in the context of the HIV/AIDS epidemic. The researcher conducted in depth interviews in order to explore themes that emerged from the interviews.

Four of the five traditional healers interviewed had passed their matriculation, the highest level of South African high school education. One traditional healer, Thandiwe had completed a six month tertiary diploma at a local technical college. She currently works as a patient advocate at a clinic situated in an informal settlement close to Cape Town. Of the remaining four traditional healers, two (Nandi and Lulu) work as nurses and also practise traditional healing. Their positions in the clinic ensured that they combined traditional healing with their care for patients who are insecure both prior to starting ARV treatment and while on ARV treatment. They provide psychosocial support and care to patients to make them feel more at ease. Flora runs a day care centre from her home in another informal settlement close to Cape Town and Xholiswa who is over the age of sixty is currently a

pensioner. The demographics and key attitudes of the healers are summarised in Table 6 at the end of the study.

4.3.2) Findings

All five traditional healers in this study demonstrated deep spiritual commitment to their profession. They said that their true calling lies in practising traditional healing. Although, two of the five claimed they would welcome more generous salaries, they were adamant that they would always practise traditional healing even it was alongside another vocation.

Generally, these five women see between ten and twenty five patients per month. One explained that generally the numbers of clients would vary according to financial status of the general client population. Their consultation fees vary according to the duration of the traditional drug treatment regimen that is prescribed as well as the number of follow up visits that clients would make. Two of the traditional healers said they charged HIV positive clients for diagnosis and also parallel counselling sessions. As Flora explained, 'an HIV positive diagnosis is complex and is usually coupled with domestic problems. Counselling sessions would be necessary to help the patient deal with domestic problems.' Flora expanded her definition of an HIV treatment process which encompasses lay psychotherapy and a traditional remedy. Interestingly, Xholiswa perceives charging HIV positive clients as an unethical procedure. She explained that 'primary health care clinics provide both voluntary testing and counselling services and ARV treatment for free. Traditional healers should not be practising healing in any other fashion'

Her attitude is an example of an assimilation of traditional healing with that of public health HIV/AIDS care and shows that traditional healing can be adapted to public health concepts.

In order to coax the traditional healers to talk about their views of ARV treatment, they were asked if they use biomedical treatment themselves. Nandi, Thandiwe and Lulu said they accessed the basic services at the local clinic and in doing so, did not see any real differences between themselves and other patients accessing the same services. Xholiswa and Flora held different views and thus provided some insight into the complexities of health seeking behaviour of traditional healers. This insight also relates to the capacity of traditional knowledge to deal with different illnesses:

> I visit the local clinic and I see a nurse there. She is most understanding. She discusses my traditional beliefs with me. I suffer from arthritis and I take medication from the clinic for it. Traditional healing cannot treat high blood pressure and so if they suffer from high blood pressure they visit clinics. I try to treat heart disease in clients with a traditional mixture of my own but this is hardly ever effective. My knowledge is not enough to treat many illnesses. Anger, stress and other strong emotions can cause heart disease and high blood pressure and I can help patients feel more relaxed if I learn more about these emotions from the nurse at the clinic. Dealing with stress can help them with their high blood pressure [Xholiswa].
>
> I do visit my local clinic but I don't listen to the staff there. I don't take their advice. Recently I broke my arm and used my own traditional medicines. I cured my arm. I refused to go to the local clinic when I thought I was having a stroke and now look at me I'm alive and well. I do respect the clinic staff and they must respect me as well [Flora].

Once coaxed into talking about HIV/AIDS, the traditional healers were asked how they perceive their role as a traditional healer in the context of the HIV/AIDS epidemic, how they make a diagnosis of HIV in a patient and how HIV/AIDS is different to other illnesses. A number of themes then began to emerge.

Bridging the gap between ARV treatment and traditional healing paradigms

All five traditional healers said their role in this epidemic was to help bridge the gap between biomedicine and traditional medicine. Furthermore all five said they were aware of the potential harm caused by many traditional sangoma prescriptions (e.g. bloodletting, purgatives or diuretics). They did not induce vomiting or diarrhoea in unhealthy patients (i.e. who are showing signs of HIV infection e.g. unnatural weight loss) but instead carried out these rituals in physically healthy patients who are

undergoing some form of spiritual unease:

> I guide my patients towards ARV treatment. I help them make decisions about their medication. I talk to them. I offer spiritual advice. I believe in ARV treatment. Other traditional healers come to me for advice and training. I have not experienced any results from them because I believe so strongly in ARV treatment [Thandi].

Recognition of the symptoms of HIV/AIDS in individual patients seemed to differ in the approaches of each of the different traditional healers. The methods of diagnosis ranged from divination, in one extreme, to reliance on the results of an HIV test, in the other:

> I communicate with my ancestors about the cause of various illnesses. I pay attention to the interpretation of my dreams. I can feel when someone is HIV positive because the spirits tell you and the soul of the person talks to you [Thandi].

> I only know if (they are HIV positive) if they have had an HIV test at a clinic and the results of the test have come back as positive. I won't know before that whether they are HIV positive. I can give them independent advice if they have other illnesses if that is what they want [Flora].

> Traditional healers differ in how they decide when someone is HIV positive. Some work as prophets and know immediately when people who approach them are HIV positive. Others listen carefully to their patients and analyse what the patient has said. Then they infer that the patient is HIV positive [Lulu].

Traditional healers who are immersed in biomedical paradigms of healing sometimes use dual healing strategies:

> We don't know (for sure if people who approach us are HIV positive). We give our (traditional) medication to patients for symptoms such as vomiting and diarrhoea. Prophets are likely to suspect more strongly that patients who approach them are HIV positive if they are exhibiting these kinds of symptoms and encourage them to go for an HIV test [Nandi].

In the way that the healers practiced traditional healing, they often amalgamated paradigms. This method applied to HIV testing where they spoke of referral of clients to VCT services:

> I am an agent who encourages my clients to access voluntary testing and counselling. Traditional medicine is too strong for HIV positive people. My clients must know their HIV status before they can have any traditional medicine [Thandi].

One of the traditional healers spoke about the idea of treating HIV/AIDS by symptoms or mixing traditional and biomedical paradigms of healing.

> When a new patient comes to see me regardless of whether I think they may be HIV positive, I send them to a nearby clinic for an HIV test. I encourage them to then come back to me for counselling. If they come back, I shake the bones to help them particularly if they are suffering from traditional illnesses (e.g. tokoloshe, bad spirits, bad luck, anger of the ancestors). If they are HIV positive, I encourage them to take their ARV treatment. While their viral counts are low and their CD4 counts are high I can be of great help to them. I also encourage my clients to have TB tests [Thandi].

Many of the quotes illustrate how these healers have incorporated biomedical constructs into their practice. This assimilation into the biomedical paradigm of healing manifests in different areas of their healing practices including in diagnosis, when and how they treat HIV positive clients, how transmission of HIV/AIDS influences treatment and prognosis.

> HIV/AIDS is different from other illnesses because it plays tricks on people's bodies. They lose weight. But still loss of weight is not enough for us, traditional healers to be sure that someone is HIV positive. Tuberculosis patients also lose weight… I encourage testing because HIV/AIDS is stronger and more dangerous than other illnesses… Before I give clients my own traditional remedies, I must make sure whether people are HIV positive or not. I must know their CD4 count after they have their test results from the clinic (Xholiswa).

> In traditional healing, different diseases are all treated differently. For example, fevers have specific treatments. Headaches, for instance are given very specific treatments by traditional healers. The aetiology of illness is crucial for choosing the treatment and HIV/AIDS can be contracted in three different ways. The modes of transmission are what determine the treatment (Flora).

Causes of HIV/AIDS heard by traditional healers

The traditional healers had heard different interpretations of the cause of illness from their clients. These included transmission by a partner (i.e. unprotected sex), financial problems, jealousy, witchcraft and anger of the ancestors.

> They say they are the victims of anger, jealousy, poison and bewitchment. In the past traditional healers used to tell their patients that they (the patients) were suffering from the anger of the ancestors. We had not yet discovered the truth. HIV is caused by much more than that [Lulu].

> I have heard different stories about the cause of illness from my HIV positive clients about the cause of illness. They talk about the break up of their marriages, their new relationships, their one night encounters. Sometimes they talk about rape and how rape causes their HIV [Nandi].

The traditional healers were tentative when it came to expressing their own beliefs about aetiology of illness, an issue that will be elaborated on in the discussion section.

Capacity of Traditional Healing to deal with HIV/AIDS

It was important to explore the issue of the capacity of traditional healing, an ancient practice to address HIV/AIDS which is a relatively new illness (only discovered in 1981). The important issue was whether or not the traditional healing paradigm has the knowledge to deal with HIV/AIDS symptoms.

> The spirits are in touch. They knew it was coming. The spirits have the wisdom, and we are the tools for demonstrating that knowledge [Thandi].
>
> It may be a new illness but it is still a sexually transmitted disease. Sexually transmitted diseases such as syphilis are old and the spirits knew how to deal with it. HIV/AIDS can be treated like any other STD [Xholiswa].

The Role of the HIV Positive Traditional Healer

The issue of the role of the HIV positive traditional healer was as significant to the healers as to the health workers in the previous study. This role was dependent on a few important factors:

> When people see these HIV positive traditional healers coming to the clinic publicly and unashamedly and disclosing their HIV status, they will probably find themselves creating much less self stigmatisation with regard to their HIV positive status (Nandi).
>
> Yes, HIV positive patients will see through the openly HIV positive traditional healers that VCT is so useful. It is so important to know one's status. It will not be seen as turning one's back on one's culture if one adheres to an ARV drug regimen. The HIV positive traditional healer can help other patients see that the HI Virus has no boundaries and no one, not even traditional healers are immune to it (Lulu).

One of the traditional healers alluded to the exceptionalism of HIV/AIDS which refers to measures taken for addressing the special stigma and vulnerability associated with HIV.

> Medical doctors treat HIV/AIDS differently from other illnesses. Thus we, traditional healers must also treat HIV/AIDS differently from other illnesses. We never tell patients they can be cured of HIV/AIDS as we could do with other illnesses. We tell the patients that they may live for many years on HIV medication but we never tell them they can be cured (Nandi).

One of the traditional healers asserted that traditional healing has the capacity to treat Illnesses, an issue that the allopathic medicine world would doubt.

> I have a story to tell that illustrates the use of traditional medicine for a medical problem. I once treated a patient whose name I cannot tell you. He had a large tumour on his scrotum and he used traditional medicine for it that I gave to him.He was also HIV positive. He had the tumour surgically removed. The traditional medicine he used helped stop the bleeding after the surgery. He healed quickly (Thandi).

Feelings about Collaboration with the Formal Public Health Sector

When asked about their opinion with regard to a potential collaboration between themselves and medical doctors, all the traditional healers were in favour of such a partnership. They all felt that a partnership between themselves and formal health workers would be useful within the context of the HIV/AIDS epidemic:

> These sangomas will be of no help to HIV positive people or the broader community if they do not tell us they are HIV positive . If they take their ARVs properly they can partner formal health workers easily. That way they can encourage patients to access voluntary and testing counselling services as well as taking their ARV treatment (Xholiswa).

> I am in favour of such a collaboration (between traditional healers and medical doctors. If I had to form such a partnership with a doctor, a patient who is HIV positive will receive his or her ARV treatment from the medical doctor. They could receive medication from the doctor for other conditions such as dehydration and TB. I would not work against the doctor. I would talk to the patient and take care of his spiritual needs (Flora).

One healer pointed out that there are doctors who are from cultural backgrounds that understand the traditional paradigm of healing. This would help collaborative efforts. For example:

> There are doctors who sometimes don't believe in traditional medicine but there are African doctors who know both systems of healing in great depth. They could enhance medical practice (Lulu).

The traditional healers expressed some conditions they felt she be laid down before

embarking upon a collaboration with formal health workers:

> One important condition is that medicines should not be refined or tested. They must stay natural because they come straight from the ancestors who tell us how the medicines must be mixed (Nandi).

> In HIV/AIDS care traditional healers and doctors must have an equal voice before we become partners (Lulu).

In order to expand this notion of a potential collaboration between traditional healers and formal health workers, the traditional healers were asked what they think the South African Department of Health should offer them. Their responses covered a broad range of issues including policy, employment and registration:

> We the traditional healers can offer our knowledge to contribute to health policy. We need to work hand in hand with officials at the South African department of health. All parties must respect each other (Nandi).

> The Department of Health must respect a multi disciplinary approach to AIDS care and treatment. Everybody must work together. No one must undermine anyone else [Lulu].

4.3.3) **Overview of findings**:

This sample of traditional healers is not representative of the broader population of traditional healers. However, the findings do give some sense of the ways that traditional healers can contribute positively to an ARV treatment roll out. In some ways the views of the traditional healers contrast the views of the health workers. For example there are issues of culture and cultural differences, the possibility of mixing the two healing paradigms and mutual trust. Some of these healers are asking for equal status with biomedical practitioners especially after they have been trained in basic HIV/AIDS care. One traditional healer requested that their medication be left natural and unrefined. These are issues that pertain to cultural (intellectual property) rights. Traditional healing may not always be capable of dealing with a fairly new illness such as

HIV/AIDS but training and encouraging collaboration with medical professionals could well strengthen HIV/AIDS care.

Table 7: Socio Demographic Characteristics of the Traditional Healers

Pseudonym of Traditional Healer	Gender	Age	Level of Education	Current Job (other than traditional healing)	Key Attitudes to traditional healing and biomedicine
Thandiwe	Female	28	Six months post matriculation diploma	Patient advocate	Accesses health services at local clinic
Xholiswa	Female	57	Grade 8	Pensioner	Charging HIV positive patients is unethical Accesses treatment for high blood pressure and arthritis HIV/AIDS is an STD and traditional healing is thus well equipped to tackle the epidemic. Treats HIV/AIDS and TB as 'neighbours'
Flora	Female		Matriculation	Coordinator day care centre	Never takes the advice of the local clinic
Nandi	Female	56	Matriculation	Nursing Sister	Accesses health services at local clinic
Lulu	Female	29		Nursing Assistant	Accesses health services at local clinic

4.4) Attitudes of HIV Positive Patients in South Africa to the use of Traditional Healing Paradigms:

4.4.1) Introduction

This section describes the experiences these patients have had with the traditional healers, their views of traditional healing practices and the ways in which alternative healing strategies have impacted on their HIV positive status and ARV treatment regimen. Of the ninety patients recruited into the study, three were ARV candidates who had not begun their treatment at the time of their interview. An additional three patients had started their ARV treatment a mere day before and thus were not eligible to answer questions about adherence.

4.4.2) Patient Study: Quantitative Findings

The prevalence of reported use of a sangoma or a traditional healer amongst the 80 conveniently sampled patients was low. Only 7 of the 80 (9%) reported usage of traditional healing services within the past year and a further 19 who used a traditional healer at some point in the past. The total number of patients who had ever used a traditional healer in the past was 26 out of 80 or 33%. The 7 respondents plus the ten who were purposively selected for having visited a traditional healer in the last year, yielded a total of 17 patients in the group who had used traditional healing in the past year and could thus be regarded as 'sangoma clients'.

Of the 17 'sangoma clients', ten out of seventeen (53%) said they had made more than one visit to a sangoma in the past year. Six out of seventeen (35%) respondents reported that the sangoma they visited was not aware of their (the client's) HIV positive status. Five out of seventeen (29%) said they had consulted the sangoma prior to starting their ARV treatment.

The reasons for consulting the sangoma were interesting and diverse. They included TB, general feelings of weakness, headaches, unnatural weight loss, bad dreams, suspicion of witchcraft, gangrene, septicaemia, vaginal infections (together with pubic lice), blindness, a leg clot and shingles.

Table 8 below shows frequency distribution of adherence in the sample:

Table 8: Adherence to ARVs amongst Patients on Treatment (n= 79)

# Adherence (Rate your adherence out of 10 over the last three days)	Percentage
1-3	1%
4-6	1%
7-9	2%
10	94%

#High adherence is scored high; Low adherence scored low.

Most patients reported high adherence.

Table 9 on the following page shows results from testing the hypothesis that visiting a traditional healer within the past year was associated with various independent variables:

Table 9: Associations between Variables and Visits made to a Traditional Healer in the Last Year

Variable	Visited traditional healer in the last year n = 17	No visits to traditional healer in last year n = 73	P Value #
Age: mean Standard deviation	35.1 (31.0-39.2)	35.8	0.35 *
Percentage Female	82.4	74.3	0.49
Percentage Disability Grant	41.18	52.05	0.42
Education	**Grade 0- 6:** 6.25 Grade 7-12: 81.25 Matriculation+: 12.5	24.31 64.87 10.8	0.65
Employed	29.4	27.0	0.84
% who Visited spiritual healer in the last year	**52.9**	**8.0**	**0.00**
% who Visited a herbalist in the last year	**11.8**	**1.34**	**0.03**
Adherence (Percentage reporting 100% adherence in the last 3 days)	100	94.1	0.84
Side effects in the last three months	6.7	1.4	0.2
Positive Effects ARV treatment	100	92.7	0.2

(Chi Squared test for difference in % between patients who visited traditional healers in the past year and patients who did not.
* t test

There was significant association between visits made to a traditional healer in the last year and visits made to a spiritual healer or to a herbalist in the last year. There was no difference in reported adherence between those who used a traditional healer in the past year and those who did not.

The most frequent (twelve out of seventeen or 71%) reported diagnosis by the sangoma was poisoning. One respondent reported that she had been told by the sangoma she consulted that the cause of her symptoms (perpetual chronic fatigue) was poison inflicted upon her while she slept at night. Another respondent who suffered from blindness and headaches said that she was told 'poisoned blood' was the cause of her illness.

Eight out seventeen sangoma clients (47%) reported the sangoma had diagnosed their illness as the result of bewitchment. Of these eight, four had been told that they had been bewitched by their mother or a close family member. Four out of seventeen sangoma clients (23 %) reported that the sangoma had told them they had angered their ancestors. Ten out of seventeen sangoma clients (59%) were told that the cause of their illness was different to that of the options presented in the questionnaire. These included that there was posthumous strife between the patient's loved ones and calling from the ancestors for the patient to become a traditional healer or a sangoma.

4.4.3: Patient Study: Qualitative Findings

Category One: Patients who have never accessed a Traditional Healer

This group consists of fifty two patients (58% of the total sample) who answered 'no' or 'never' to the question about whether or not they had accessed a traditional healer within the last year. These patients were not followed up for qualitative in depth interviews. They were asked the reasons for their choice of healing strategy. They then elaborated that they had never accessed a traditional healer and some qualitative data was extracted from them by means of a few 'open ended' questions that were placed in the questionnaire. These questions

probed their opinions and perceptions of traditional healing practices. Although a clinic based study will inevitably recruit patients who are immersed in the biomedical paradigm of healing, the respondents in this group still offered insight into the complexity of health seeking behaviour of HIV positive patients.

Most of the patients in this group said they did not believe in traditional healing. As one patient explained, 'seeing a traditional healer was never an option for me.' I went straight to a clinic when I found out I was HIV positive.' Another patient alluded more directly to her belief value system: 'I only believe in the medical doctor'.

There were more complex reasons for the choice of these patients not to access any form of traditional healing service. These included psychological issues (such as trust, fear, religious belief and childhood experiences) as well as issues related more directly to treatment (the perceived incapacity of traditional healing to deal with HIV/AIDS, possible adverse drug interactions and lack of scientific evaluation of traditional medicine). These themes are explained in more detail below.

Childhood Influence

Some patients in this group said that as the importance of traditional healing had not been instilled during their childhoods, they had no need to access these services during adulthood. More specifically, they spoke of the health seeking strategies they had engaged with as children as significant influences in moulding their adult behaviour.

My parents did not believe in traditional healers. Whenever we got sick as children, we were taken to a doctor (Female patient, Du Noon)

I do not believe in sangomas. I was raised by my parents not to believe in sangomas. I heard on the radio the other day, a woman saying she can help spots of HIV positive people with a special soap. How can I believe this kind of untruths? (female patient, Gugulethu)

Religious Belief

Religious belief and the influence of the church to which they belong were mentioned as significant influential factors by a number of respondents. One patient explained that the church to which she belonged (the Universal Church of South Africa) actively discouraged its members from visiting sangomas. She said that the church's members were constantly exposed to the 'teachings of Jesus Christ and the entire congregation is for Jesus':

> Only God can heal. Not sangomas. My child who is HIV positive visited a sangoma who told her there was something evil inside her body. She claims the sangoma helped her. But I believe that God and her ARV treatment helped her. I respect her belief but I am much more comfortable in the clinic or the hospital. Sangomas eat money (Female patient, Gugulelthu).

> According to our (Christian) religion, we can't go to traditional healers. We don't believe in them. The church is aware that I am HIV positive and does not allow me to see sangomas. I am only for Jesus (Female patient, Du Noon).

Trust

There are patients in this group who said they do not trust traditional healers. They believe that traditional healers are merely entrepreneurs who promote their healing practices for the purposes of profits.

> Traditional healers just want money before they can treat you. I don't trust them
> In 1997, I found out I was HIV positive. A sangoma asked me if I wanted to come to her for treatment. When I said no, she asked me if I wanted to die. ARVs are so good. I have no need for a sangoma. They lie! (Female patient, Du Noon)

Belief in Effectiveness of Traditional Medicine (by others)

Respondents expressed fear that traditional practices are potentially harmful. It is fear of these practices that influence a decision not to consult with a traditional healer.

> My friend was HIV positive and staying in Umtata, Transkei. She became very ill and used a herbal mixture that a sangoma had given her. She never took ARV drugs because she believed so strongly in traditional healing. Eventually her mother took her to a doctor who had her hospitalised. She was very sick from the complications caused by the interactions between the

> ARV drugs and the traditional medicine. She died in hospital. There are many stories like this (Female patient, Gugulethu).

False Claims to have the cure for HIV/AIDS

Traditional healers who falsely claim to have the ability for HIV/AIDS seemed to have been an important influence in shaping the health seeking strategies of some of the patients in this group;

> Never in my life have I been to a Traditional Healer. I don't believe in Traditional Healers. They say they can cure HIV. This is not true' (Female Patient, Gugulethu)

Similarly a view that traditional healing does not have the capacity to deal with HIV/AIDS emanated from this group:

> Sangomas can't make an HIV positive diagnosis. They tell HIV positive people that they are dirty. They encourage them to slaughter a goat. How can that help HIV positive people? I have two friends who are HIV positive who consulted sangomas. These two people did not accept they are HIV positive. They refuse to take ARV drugs and they getting sicker and sicker. Once I was asked at the clinic do I take traditional medicine and I said I don't believe in it (Female Patient, Gugulelthu).

> I have heard of sangomas treating other illnesses e.g. joints pain. Not HIV though (Female Patient, Gugulethu)

Inappropriateness of Traditional Healing Paradigm for Western Illnesses

One patient explained that traditional healing methods are not really appropriate when it comes to HIV/AIDS care

> Sangomas are there to help people with problems. Like jealousy and witchcraft. Not HIV (female patient, Gugulethu)

Issues around Scientific Testing

As many patients in the study were also previous participants in clinical trials which take place at these clinics, they are aware of the necessity of scientific evaluation of all drugs. As traditional medicine has never been scientifically evaluated, many patients queried its therapeutic quality or credibility:

> Sangomas only want us to use their traditional medicine. How should I know how that imbiza (water and Traditional medicine) is if they don't go to the lab (female patient, Gugulethu)
>
> I don't like Traditional Healers. I don't know where their traditional medicine comes from- if it is real or not (female patient, Gugulethu)
>
> Sangomas make you ill. They give you herbs. They don't know what is going on. They don't test their medication. They just give it to you (Male Patient, Gugulethu).

The categories of reasons as to why this group of patients had never accessed a traditional healer are summarised in Table 9 below:

Table 10: Reasons given by Patients who have never accessed a Traditional Healer for their choice
Childhood Influence
Religion
Inappropriateness of Traditional Healing Paradigms for 'Western Illnesses'
Issues around scientific testing
False claims by traditional healers to have the cure for HIV/AIDS
Belief by others in the effectiveness of traditional medicine
Issues around trusting traditional healers

Category 2: Patients who have consulted a Traditional Healer prior to the Interview or Prior to starting ARV treatment

The second identifiable group of patients consists of thirty six patients who had previously consulted a traditional healer. Some of these patients expressed positive opinions of traditional healing services while others were much more sceptical of traditional healers. Four of the patients in this group were affiliated to the profession of traditional healing. One female patient spoke of her experiences of training to become a sangoma:

> I was once a trainee sangoma. My uncle was going to pay my fees for my sangoma training. But he died. This was before I knew I was HIV positive. Suddenly, I developed a rash all over my body. Shortly after, I found out I was HIV positive. I did not want to become a sangoma anymore. If the ancestors wanted me to become a sangoma, they would not have allowed the HI Virus to get into my body. You [the researcher], you ask a lot of questions but you must know that the witch doctors are not good.

Only one patient had consulted a traditional healer for advice about HIV/AIDS. Shortly after the consultation she decided to immerse herself fully into an ARV treatment regimen. The traditional healer's advice had made 'no difference' to how she was feeling.

Family Pressure

After the results of an HIV positive diagnosis, many patients experience pressure from family members to visits a traditional healer. One patient who now works as an ARV counsellor in the Gugulethu clinic spoke of the pressure she experienced from family members after she found out she was HIV positive:

> In 2003, I went to a traditional healer with my aunt. I knew I was HIV positive then and my aunt was worried. I wanted to please my aunt because she was so supportive of me so I agreed to go to the traditional healer with her. The traditional healer wanted to give me a bottle of greenish liquid to drink from. I was too scared to drink from it. I came to the clinic after that for my ARV treatment instead. Sangomas won't tell you what is in these bottles they

> give their clients. They just tell you they have the cure for HIV/AIDS (Female patient, Gugulethu).

Implausible Theories of Illness Aetiology

There were patients in this group who said the causes of their illness as explained by the sangoma were not credible. This was an influential factor in determining their choice to adhere to ARV treatment.

> The sangoma said I was bewitched by my neighbours' family. I once woke up one morning with my hair dreadlocked on one side and went to my church to find out the meaning of this. At the church they told me that the ancestors want me to become a sangoma but I didn't believe them (Female patient, Du Noon).

Negative Encounters with Traditional Healers

There were a number of patients in this sample who had had a negative experience with a traditional healer. This encounter influenced their perception of traditional healing strategies:

> I was diagnosed as HIV positive in 1999. My mother was so sad about this diagnosis and worried so she took me to a woman sangoma that she knew. This woman gave me 2 bottles which she said were a cure for HIV/AIDS. She told us that HIV was really nothing like we are made to believe, not a serious condition at all... At the time, I knew nothing about ARVs so I listened to the sangoma and drank the contents of the two bottles. I lost so much weight and suffered chronic diarrhoea. I became so confused about what action to take (Female Patient, Gugulethu).

Fear and Vulnerability

Two patients spoke of the fear they felt when visiting a traditional healer:

> I refused to use the traditional healer's treatment. I was afraid to use the enema. The traditional healer never knew I was HIV positive. I did not tell her. I was scared she might hurt me because I am HIV positive (Female Patient, Du Noon).

There is also the possibility that the traditional drug regimen prescribed by the traditional healer makes no difference to the quality of the patient's life:

> The traditional healer said that my illness was caused by idiliso (witchcraft). By then I knew I was HIV positive as I had had unprotected sex without using a condom. When the traditional healer gave me traditional drugs I felt no different. There was no need for me to visit a traditional healer again (Female Patient, Du Noon).

> An HIV positive diagnosis at a clinic or a hospital from the voluntary counselling and testing process is an end to the confusion. After this diagnosis there is no need to visit a sangoma. I myself stopped (going to a sangoma) immediately after I found out I was HIV positive (Female Patient, Du Noon).

Positive Aspects of Traditional Healing

Notwithstanding negative experiences there were also positive thoughts about traditional healing emerging from this group of patients. One patient said that he had used traditional medicine to effectively treat his asthma symptoms but since starting ARV treatment he had been reluctant to mix ARV treatment with traditional medicine. Another patient said he had sought help from a sangoma when his child cried continuously. The sangoma helped him alleviate this problem by suggesting he perform a ritual for his ancestors. A pregnant female patient who had experienced fertility problems prior to her interview reported that visiting a traditional healer who seemed to fulfil a psychotherapeutic function had helped her enormously. She said that the traditional healer had been accommodating of her HIV positive status and had encouraged her to adhere to her ARV treatment regimen. Another patient explained that he had visited a traditional healer for advice about handling a domestic problem. He explained:

> The traditional healer was able to tell me why I had this problem and what had caused it. I don't need the traditional healer for my HIV though. I have ARV treatment for that (Male patient, Gugulethu).

One interesting aspect of this group was finding four patients in this group who reported that they were affiliated to traditional healing as a profession. In other words, they had undergone training to become a traditional healer or they had themselves practised traditional healing.

One female patient who had been deemed eligible to start ARV treatment was also a trainee traditional healer at the time of her interview. She said that she trusted the advice of the

traditional healers in the Eastern Cape and made contact with them whenever possible. Recently she had sought advice from a renowned, respectable traditional healer in the Eastern Cape for her epilepsy and 'a worm infestation that had gone to her head'. She has never consulted another traditional healer for advice about her HIV/AIDS diagnosis or associated problems. Instead she says that she 'cannot wait to start ARV treatment. It is the only treatment that will help her now'.

A married couple practising as sangomas were recruited when they came to fetch their ARV treatment at the Gugulethu clinic. They seemed to assimilate what they learn at the clinic into their traditional healing practice.

> Only our HIV negative clients as well as clients who do not know their HIV status can use traditional medicine. We send our HIV positive clients to the clinic for ARV treatment. We only used traditional medicine ourselves before starting ARV treatment. We have the ability to recognise opportunistic infections such as TB in many of our clients. We refer clients suffering from these to the clinic as well (Male Patient, Gugulethu).

> We can't give traditional herbs to an HIV positive person. Traditional medicine is too strong for HIV positive people. Many traditional healers we know are not educated and their practices can be harmful to HIV positive people. Traditional rituals such as a blanket over the client's head and breathing in mixtures but not drinking them are fine for HIV positive clients (Female Patient, Gugulethu).

These results show that it is feasible to train traditional healers in ARV care and that they can easily support an ARV roll out and can encourage patients to adhere to their treatment. Table 10 summarises the reasons given by respondents for their choice to no longer visit traditional healers.

Table 11: Reasons given by patients who no longer access Traditional Healing Paradigms for their choice
Resistance to family pressure
Implausible theories of illness aetiology
Negative encounters with traditional healers
Fear and vulnerability

Category 3: Patients who are actively crossing between the two systems of healing

The final group consists of two patients who were actively crossing between ARV treatment and their traditional healer. Three principal themes emanated from the data involved: misunderstanding, confusion and credibility of traditional healing.

The first theme illustrated that the side effects of ARV therapy could result in patients feeling confused about their treatment. They may believe the side effects are actually an illness of their own.

Misunderstanding of the Side Effects of ARV Therapy

> I visited a traditional healer because I felt I wasn't getting any better by using ARVs. I thought the ARVs were making me feel worse. The traditional healer that I visited gave me some medication. I vomited. I had diarrhoea. I was eventually hospitalised at Somerset hospital because of all these complications. But I still don't know what can help my headaches (Male Patient, Du Noon).

There is also the possibility that patients may be confused by the symptoms of HIV/AIDS and believe that their illness is caused by a cultural duty.

Confusion

> I am so confused. The Traditional Healer tells me I am sick because my ancestors are calling me to become a traditional healer. The clinic tells me I am sick because of a virus called the HI Virus. The traditional healer does not advise me to come to the clinic. Instead he advises me to drink Xhosa beer, slaughter goats and cows. When I feel better, I am not sure if the clinic is helping me or the bottle of traditional medicine that the traditional healer has given me... The Traditional healer gave me medicine to clean my blood and to make me stronger and suggested I perform a ritual for her ancestors. The traditional drug regimen helped me a lot. The traditional healer knew I was HIV positive and I told the traditional healer I was taking ARV drugs. I take the traditional drug regimen at the same time that I takes her ARV drugs. I know that my life has improved on ARV drugs but I still experience TB, rashes as well as anxiety. This is why I visit the traditional healer. Because of my anxiety and my confusion (Female Patient, Du Noon).

Stigmatisation of HIV positive people is a prevalent issue. Attending ARV services could result in disclosure of positive status and subsequent stigmatisation.

Stigma

> I met another patient in this (Gugulethu) clinic who believes that only Jesus can save her and that a mixture she got from a sangoma will help her. She only comes to the clinic to have her CD4 counts taken. She doesn't take ARV drugs. At the beginning when patients are diagnosed HIV positive, to come to a clinic means you are admitting you are HIV positive. Visiting a traditional healer at first does not have the same consequences. Many people choose to visit a traditional healer first because they are afraid of HIV stigma (Female Patient, Gugulethu).

It is clear that confusion about the symptoms of HIV/AIDS and the initial effects of the ARV

treatment therapy could encourage a patient to cross between the two systems of healing. Stigma is also a prolific issue that affects HIV/AIDS patients' willingness to disclose their status.

Overview of Findings

In conclusion it is clear that although there are patients who have never used a traditional healing service, there are others who have may visit a traditional healer during their initial phases of their HIV positive diagnosis. The patients who have ties with traditional healing practise themselves demonstrate particularly interesting healing strategies. They claim they do not use untested traditional treatment on HIV positive patients or to take this treatment themselves. They also claim they encourage clients to access VCT services at local clinics and in the event of an HIV positive diagnosis to adhere to ARV treatment.

Chapter 5: Discussion

The discussion section draws out central issues raised by the respondents in the study and then relates these findings to broader literature sources on the topic.

There are similarities and differences across the three sub-studies. The health worker study showed that they have major concerns about traditional healing practices. These include the possibility of toxic interactions between ARV treatment and traditional medicine. Some of the health workers had had experiences of patients lapsing into treatment failure due to use of traditional medicine and lack of adherence to their ARV treatment. Some health workers adopt more conciliatory approaches than others and tolerate patients who wish to access a traditional healing service while taking ARV treatment. This attitude is in the hope that the patients will eventually realise that ARV treatment is the most effective medication for them. Similarities can be drawn between these findings and those of Nsubuga et al (1998) who found that formally trained health workers in Kampala, Uganda recognized the importance of the role of traditional healers in public health care.

In contrast, the lay health workers i.e. the patient advocates and ARV counsellors seemed to completely undermine the role of the traditional healer in HIV/AIDS care. They support an effective ARV roll out that is monitored by clinic staff and see a marginalized role for traditional healers in this respect. They believe that traditional healers are unwilling to cooperate in the clinic setting by adapting their practices to measures that are conducive to the clinic's procedures. These lay health workers advise patients of the potential adverse interactions between ARV treatment and some types of traditional medicine.

The traditional healers interviewed as part of the sub study admitted that traditional medicine and many traditional practices can be problematic when used by HIV positive patients and that traditional healing paradigms are not always capable of dealing with HIV/AIDS. However these healers were of the opinion that they can contribute to successful ARV treatment and prevention programmes. Both the health workers and the traditional healers seemed to be in favour of collaborating with one another (a minority of health workers were opposed to such a collaboration) but there were certain conditions that they stipulated. In the case of the health workers, issues about training in biomedical HIV/AIDS care were raised. One doctor was of the opinion that traditional healers could have a role in the psycho social aspects of treatment programmes. The traditional healers, on the other hand, discussed issues around mutual respect as their principal condition for collaborating with health workers. Trust emerged as an important issue and was discussed by the traditional healers as a pre requisite for collaboration. The findings of this sub study are dissimilar to those reported by Richter et al (2003) who found that traditional healers are insistent that their strategies are adequate for dealing with HIV/AIDS.

A similarity in responses across groups was the recognition of the role of the HIV positive traditional healer in bridging the gap between the biomedical and traditional paradigms of healing. A traditional healer who is HIV positive and who is compliant with the ARV drug regimen has the ability to assist in strengthening the ARV roll out. This finding is consistent with Henderson's (2005) study of two HIV positive traditional healers who in acknowledging that traditional healing is not capable of dealing with the HIV/AIDS epidemic on its own indicated willingness to collaborate with the formal public health sector so that they can provide adequate HIV/AIDS prevention efforts and care.

The patient study produced some interesting findings from both the quantitative and qualitative components. In contrast to Nattrass (2005 b), this study failed to find a significant association between gender (being female) or receipt of a disability grant and visits made to a traditional healer. This difference may arise because the majority of the sample was actually female so comparison lacked statistical power. It is difficult to assemble or recruit a sample of HIV positive patients attending a clinical service that is representative of both genders because the uptake of these services by women is higher. Women also make use of additional services that are associated with ARV services (e.g. reproductive health care and Prevention of Mother to Child Transmission (PMTCT) services). Nonetheless, in this study prevalence of ever using traditional healing services was 32.5%, approximately similar to findings of Banda et al (2007) in Zambia where 30% of pregnant women reported visiting a traditional healer in the past. This Zambian study also found that pregnant women who were HIV positive and visiting traditional healers were less likely to adhere to PMTCT treatment than women who were not accessing traditional healing services.

However, the current study found no significant association between visits made to a traditional healer and adherence to ARV treatment. In general, reported adherence was very high with only two patients in the entire sample admitting that they had missed taking their pills within the last month. Similarly, with regard to knowledge of ARV treatment and its effects on the body, only two patients seemed to be slightly misinformed. The study therefore lacked statistical power to determine any associations with usage of traditional healing services and adherence. Most of the patients said that ARV treatment had had a positive effect on their lives and few had experienced side effects from their ARV treatment within the last month.

However a significant association was found between visits made to a herbalist, and visits to a spiritual healer and visits to a traditional healer in the past year. It is expected that people visiting a traditional healer would also access other forms of alternate healing.

Limitations encountered in the study as a whole

There were a number of limitations encountered in the traditional healer sub study and the patient sub study.

With regard to the traditional healer sub study, there was difficulty in accessing traditional healers who were not already engaged with the health services. These traditional healers are contactable through the organizations with whom they are affiliated. Traditional healers who are immersed in their own paradigm of healing and who are unfamiliar with biomedicine are generally aloof. There is the possibility that they reside in rural areas and are therefore uncontactable by telephone.

With regard to the patient sub study the limitations were the nature of the study, the geographical location of the study sites, the way that the question was posed, the perception of the respondents of the interviewer and the credibility of the respondents. The patients were a sample of a population that is subject to selection bias.

Perception of the Respondents of the Interviewer

The interviewer was of a different cultural background to the respondents. This may have impacted on the interviews. Perhaps respondents were less likely to impart information about visits made to a traditional healer to an interviewer of a different cultural background. This

theory is substantiated by the association found between visits to a traditional healer in the past year and visits made to a herbalist in the past year.

Nature of the Study

Firstly a clinic based study will inevitably recruit patients who are at the very least partially immersed in biomedical paradigms of healing. Thus it was challenging to recruit patients who were using traditional healing paradigms. The results are based on the experiences and opinions of a selected group of patients.

Secondly the clinic environment may also be inherently oppressive. Respondents may not have felt comfortable enough to tell the truth when the interview was conducted in the very place where they are advised against the use of traditional medicine and traditional healing paradigms particularly when evidence from the focus groups suggests that the personnel at the clinics appear to actively discourage patients from using traditional medicine.

Posing of the Question

Lastly the questionnaire asks respondents if they had visited a sangoma or a traditional healer in the last year. This time frame is inherently limiting. However the researcher countered this by the technique of asking the respondents what their reasons are for their choice of healing strategy.

Chapter 6: A Human Rights Approach to the Place of Traditional Healing Systems in ARV Rollout

This chapter provides some suggestion for an ARV treatment policy that respects cultural rights in relation to traditional healing. The suggestions are guided by the analytical framework of Mann and Gostin (1999). Three potential policy options for addressing the place of traditional healing in ARV roll out are possible:

1) The patient will have no choice with regard to treatment. The patient will be actively discouraged from using a traditional healer. The patients treatment will be discontinued if he or she is found to be using a traditional healer.

2) The patient will have free choice of either ARV treatment or traditional medicine.

3) The patients' choices will be limited. They will be allowed to access a trained traditional healer (that is accessible to the clinic's ARV programme) but will have to take ARV treatment. This process will be closely monitored by the ARV team.

Each of these options will be discussed under the elements of Mann and Gostin's 1999 tool for policy analysis.

<u>Step 1: Clarify the Public Health Purpose</u>

All three policies have the same objective which is to improve HIV/AIDS care.

Step 2: Evaluate likely policy effectiveness

The first policy option is not an effective policy as the patient may still attempt to access a traditional healing service. There is no practical way to stop these patients from seeking the services of a traditional healer. Patients may simply lie to staff when asked about use of traditional healing. The policy could further discourage HIV positive patients from seeking ARV care as they may feel restricted at the facility.

The second policy option which is antithetical to the first and gives patients free choice of treatment options is potentially not effective. The policy does not address issues of drug toxicity and adverse interactions. Patients may not be adequately informed of these risks and may miss access to ARV care. Health workers could face crises similar to that of the patient who died from a prescription given by a sangoma described in the health workers sub study. There is no epidemiological evidence to suggest that this policy option would result in the desired policy objective.

The third policy option which was drawn directly from the results of the health worker study may be relatively effective in comparison to the other two options. The traditional healer will operate in a psychosocial role and will be supporting the ARV treatment rollout. The traditional healer may express resistance at the constraints placed on their role and function and would have to receive counselling to try to gain their compliance with the rules of the policy. The traditional healer would have to be monitored and trained. Health workers at

facilities where this policy is to be implemented would have to receive guidelines of how to collaborate with traditional healers on the basis of mutual respect. However, once again, there is no epidemiological evidence to suggest that this policy will result in the desired public health objectives. Further research would however be needed to monitor and evaluate the impact of such a policy on ARV adherence and care.

Step 3: Determine whether the public health policy is well targeted

The first policy option is not well targeted. It is aimed at HIV positive patients attending ARV facilities. HIV positive patients not attending ARV facilities would not be reached. The second policy option is much the same as the first in terms of the population it would target. The third policy option is well targeted at HIV positive patients and could bring patients into the health system who may not have entered as yet.

Step 4: Examine the policy for human rights burdens

There are immense human rights burdens if the patient is given no choice with regard to treatment and traditional healers are prevented from practising their profession and healing strategies, violating both their cultural rights and their rights to economic activity. With regard to the second policy option, patients may not be adversely affected by human rights burdens directly. However, the development of treatment resistant HIV would be a burden on society in general and possibly the patient's family and caregivers. With regard to the third policy option, though the human rights burdens are not immense, there is still potential to discredit cultural practices. There is also potential for toxicity or ARV failure in a small number of users. One of the traditional healers in the second sub study raised the issue that they did not want traditional drugs to be tested or refined. This raises challenges for a human rights system needing to protect intellectual property rights of indigenous people.

Step 5: Determine whether the policy is the least restrictive alternative that can achieve public health

The second policy option by definition is not a restrictive policy but in the long term may adversely affect access to HIV/AIDS care for patients and others in the community. With regard to the third policy option, there is some restriction on traditional healers in that they are required to limit their practices. However it is less restrictive than the second option.

Step 6: If a coercive public health measure is truly the most effective, least restrictive alternative, base it on the significant risk standard

There is presently no evidence for cost effectiveness of any of the policy options. However, the third policy option appears to show the best ratio of benefits to harms and thus is the most feasible policy option.

Step 7: If a coercive measure is truly necessary to avert a significant risk, guarantee fair procedures to persons affected

Fair procedures would have to be implemented for all the policy options. There would have to be adherence counselling and training for health workers and traditional healers.

Overview of Analysis

The human rights analysis has shown that the third policy option that suggests traditional healing practices can be modified to operate optimally in the ARV roll out is by far the most

feasible of the three options presented. Of all the policies it affords most for synergy between public health and human rights. Further research will have to be implemented to monitor the effectiveness of the third policy option.

Chapter 7: Conclusion and Recommendations

In conclusion it is clear that while health workers would prefer that traditional healers are left to conduct rituals in the event of a collaboration, traditional healers request that a partnership be based on mutual trust and equal status. Although the majority of patients recruited in this study had never accessed a traditional healer or no longer wished to, many had previously done so and a minority of patients were crossing between the two systems of healing. Given other research suggesting widespread use of the systems in South Africa, this suggests that traditional healers do have a role to play in ARV roll out.

A number of issues need to be addressed to ensure effective collaboration between traditional healers and formally trained health workers. Firstly there will be a need for an attitude change on behalf of health workers and traditional healers. Health workers will need to consult with a body like the Traditional Healers Organization (THO) to ensure they receive adequate training to collaborate with traditional healers. Traditional healers will have to attend training at organizations like HOPE, a Non Governmental Organization that is based at Tygerberg hospital in Cape Town that provides HIV/AIDS education for traditional healers.

Provincial Departments of Health HIV/AIDS directorates should be prepared to develop a policy for integrating trained traditional healers into ARV care. Recommendations arising from the study can be incorporated into this policy:

- Trained traditional healers should be incorporated into ARV care
- Health workers should receive guidelines to assist them in collaborating effectively with traditional healers

- The issue of this intersection between traditional healing and HIV/AIDS should be integrated into medical curricula at both undergraduate and post graduate level. Primary health care courses are suited to provide lectures and course material on this issue. This would prepare students for engaging with traditional healers after they graduate.
- Lay health workers will need to be less dogmatic and engage with patient concerns regarding traditional healing. They could advise patients to seek traditional healing for psychosocial problems but to adhere to ARV treatment at all costs. The lay health workers should undergo training and workshops to foster their objectivity, sensitivity and self awareness.
- The role of the HIV positive traditional healer emerged quite strongly from the three sub studies. There is potentially a role for these traditional healers. They could work as community health workers or as patient advocates. They are well placed with their understanding of what it is like to live with HIV/AIDS to assist in ARV roll out procedures.
- Further research should be conducted to ease the transition of collaboration. This research could take the form of quantitative or qualitative designs to extract attitudes and opinions of health workers, patients and traditional healers to collaborating in the area of ARV care. Collaborations should be monitored and evaluated.
- Research projects should be widespread and be conducted in a number of clinics in different areas. Studies in different locations would extract data about the needs of different communities with regard to traditional healing. What this would mean in practice is that where there is a need, clinics and

community health centres could train individual healers to assist them with ARV care. Studies should be conducted outside clinics.

- The Human Rights Commission could be asked to provide documentation on protecting cultural rights in this particular context.

There are important health care benefits for improving ARV care in South Africa that could be achieved if policies addressing the role of the traditional healer could be developed. This study has suggested ways whereby respect for cultural rights can be feasibly incorporated into public health programmes for HIV/AIDS care.

References:

Abdool, K. S. 1994. *Bridging the gap: a potential for healthcare partnership between African traditional healers and biomedical personnel in South Africa.* Pretoria, South Africa: Medical Association of South Africa.

Ashforth. A. 2001. *Madumo: A man bewitched.* Chicago: University of Chicago Press.

Ashforth, A. 2005. *Witchcraft, violence and democracy in South Africa.* Chicago : University of Chicago Press.

Ashforth, A. and Nattrass, N. 2005. Ambiguities of 'culture' and the antiretroviral rollout in South Africa. *Social Dynamics.* 31(2): 285- 303

Banda Y., Chapman V. and Goldenberg RL. 2007. Use of traditional medicine amongst pregnant women in Lusaka, Zambia. *Journal of Alternative and Complementary Medicine*

Bekker, L.G. (Linda-Gail.Bekker@hiv-research.org.za). 2007. Opening speech of Hannan Crusaid clinic, Gugulethu, 2005. [Personal e-mail, 04 April 2007] to Ms Sumaya Mall (sumaya.mall@gmail.com).

Cameron, E. 2005. *Witness to AIDS.* Cape Town: Tafelberg.

Cass, H. 1998. *St. John's Wort : nature's blues buster.* Garden City Park, New York: Avery Publishing Group.

De Cock, K. 2002. Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century. *Lancet.* 360 (7): 67 - 72

Devenish, A. 2005. Negotiating healing: understanding the dynamics amongst traditional healers in Kwa-Zulu Natal as they engage with professionalisation. *Social Dynamics.* 31(2): 243-276

Dorrington, R. Johnson L. Bradshaw D. and Daniel TJ. 2006. *The demographic impact of HIV/AIDS in South Africa: national and provincial indicators for 2006.* Cape Town: Centre for Actuarial Research University of Cape Town Medical Research Council Actuarial Society of South Africa.

Edington, M.E. Sekatane CS and Goldstein SJ. 2002. Patient beliefs: do they affect tuberculosis control: a study in a rural district of South Africa. *International Journal Tuberculosis and Lung Disease.* 6(12): 1075 – 1082 .

Foyaca-Sibat, H., Del Rio-Romero, A.I., and Ibanez-Valdes, L de F. 2005. Prevalence of epilepsy and general knowledge about neurocystierosis at Ngangelizwe Location South Africa.. *Internet Journal of Neurology.* 4(1): 906-16 [Online]. Available:

http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ ijn/vol4n1/epilepsy.xml [2007, September 5].

Garner, P. and Volmink J. 2003. Directly observed therapy for treating tuberculosis. *Cochrane Database Systematic Review.* (3): 1-25.

Gill C. ,Hamer DH. ,Simon JL. ,Thea DM. and Sabin LL. 2005. No Room for Complacency about Adherence to Antiretroviral Therapy in Sub Saharan Africa.. *AIDS.* 19(12): 1243 – 1249.

Green, E. 1994. *AIDS and STDs in Africa: bridging the gap between traditional healing and modern medicine.* Boulder, Colarado: Westview Press.

Gruskin, S. and Loff, B. 2003. Do human rights have a role in public health work? *Lancet.* 360(9348): 1880

Harper, M.E. 2004 Traditional healers participate in tuberculosis control in the Gambia. *International Journal of Tuberculosis and Lung Disease.* 8(10): 1266-68.

Henderson, P. 2005. A Gift without shortcomings: healers negotiating the intersection of the local and the global in the context of HIV/AIDS. *Social Dynamics* 31(2): 24 - 53

Heymann, J. and Sell, R.L. 1999. Mandatory Public Health Programmes: To What Standards Should they be Held? *Health and Human Rights* (4): 193 – 203.

Homsy, J. et al. 2004. *Traditional Health Practitioners are key to scaling up comprehensive care for HIV/AIDS in sub Saharan Africa.* AIDS. 18(12):1723-1725

Iliffe, J. 2006. *The African AIDS epidemic: a history.* Oxford: Oxford University Press.

Kapp, C. 2004 Nigerian state promises to end Polio vaccine boycott. *Lancet.* 363(9424): 709

Kiguba, R. 2005. Uganda: use of traditional medicine interfering with ART adherence. *PlusNews.* March, 27. [Online]. Available: http://www.plusnews.org/Report.aspx? [2007, May 5].

Liddell, C. et al 2005. Indigenous representations of illness and AIDS in Sub Saharan Africa *Social Science and Medicine.* 60(4): 691 -700

Liverpool HIV Pharmacology Group. 2007. *Drug Interaction Charts.* [Online]. Available: http://www.hiv-druginteractions.org/frames.asp?drug/drg_main.asp. [2007, September 6].

London. L. 2002. Human rights and public health: dichotomies and synergies in developing countries? examining the case of HIV in South Africa. *Journal of Law, Medicine and Ethics.* 30(4): 677 – 691.

Mann, J. et al. (Eds.). 1999. *Health and human rights: a reader.* New York: Routledge.

Maughan-Brown, B. 2007. Experiences and perceptions of HIV/AIDS related stigma amongst people on antiretroviral treatment in Khayelitsha, South Africa. Working Paper. Centre for Social Science Research, University of Cape Town. (Unpublished).

Nattrass, N. 2005a. The quest for healing in South Africa's age of AIDS. *Social Dynamics* 31(2) 1-23

Nattrass, N. 2005b. Who consults sangomas in Khayelitsha: an exploratory quantitative analysis. *Social Dynamics.* 31(2) 161 - 183

Ngubane, H. 1977. *Body and mind in Zulu medicine: an ethnography of health and disease in Nyuswa- Zulu thought and practice.* New York: Academic Press.

Nyika, A. 2007. Ethical and regulatory issues surrounding African traditional medicine in the context of HIV/AIDS. *Developing World Bioethics.* 7(1)1: 25 -34.

Orrell, C., Bangsberg DR. ,Badri M. ,Wood R. 2003. *Adherence is not a barrier to successful ARV therapy in South Africa. AIDS.* 17(9): 1369-1375.

Osler. M and White C. [megosler@gmail.com and catherineawhite@gmail.com]. 2007. [Personal email, 15th August 2007] to Ms Sumaya Mall (Sumaya.mall@gmail.com)

Peltzer. K, Mngqundaniso N. and Petros G. 2006. A controlled study of an HIV/AIDS/STI/TB intervention with traditional healers in KwaZulu-Natal, South Africa. *AIDS and Behaviour.* 10(6):683-690.

Powell, A. 2006. Rasta children not allowed at school. *Cape Times. 18/01/2007:5*

Singh. JA, Upshur. R and Padayatchi.N XDR TB in South Africa: No Time for Denial or Complacency in *Plosmedicine.* 4(1): 19-25 [Online] Available: http://www.plosmedicine.org

South Africa. 1996. *Constitution of the Republic of South Africa as amended, Act 108 of 1996.* [Online]. Available from SABINET Online at http://www.lib.uct.ac.za/datahosts.htm [2007, September 6].

Toubia, N. 1994. Female genital mutilation and the responsibility of reproductive health professionals. *International Journal of Gynaecology and Obstetrics.* 46(2): 127-135.

Vermani, K. and Garg, S. 2002. Herbal medicines for sexually transmitted diseases and AIDS. *Journal of Ethnopharmacology.* 80(1): 49- 66.

Wanyama, J. et al. 2007. Belief in divine healing can be a barrier to antiretroviral therapy adherence in Uganda. [Abstract]. *AIDS.* 21(11): 1486-1487.

Weiser, S.D. et al. 2002. *Determinants of ARV Treatment Adherence among patients with HIV and AIDS in Botswana,* International Conference AIDS.

Wreford, J a. 2005. We can help! a literature review of current practice involving traditional African healers in biomedical HIV/AIDS interventions in South Africa. *Social Dynamics*. 31(2): 90 - 117

Wreford, J b. 2005. The role of the sangoma in contemporary South Africa. PhD Thesis. Department of Social Anthropology, University of Cape Town.

Appendix 1: In-depth Interview Guide (Health Workers)

1) Have you noticed evidence in your ARV patients that they may be using traditional medicine?
2) Having answered question (1) how are you handling the traditional medicine issue in your patients?
   (Probe: what do you tell your patients about using traditional medicine?)
3) What have you heard traditional healers telling clients about the cause of HIV/AIDS?
   (Probe: jealousy, witchcraft)

4) Have you heard of traditional healers prescribing treatment for opportunistic infections?

5) Have you heard of traditional healers violating the rights of their clients?

(Probe: the claim that having sex with a virgin can cure HIV/AIDS, does that come from traditional healers?)

6) Have you treated an HIV positive traditional healer before? How do you perceive the role of the HIV positive traditional healer in bridging the gap between traditional healing and biomedical HIV/AIDS care?

7) What are your feelings about a potential collaboration between traditional healers and formally trained health care workers?

8) Any further comments?

Appendix 2: In-depth Interview Guide: Focus Groups

1) Please describe the home visits you have made to ARV patients.
2) What do you discuss with the ARV patients at the clinic?
3) Have you noticed evidence in your ARV patients that they may be using traditional medicine?
4) Having answered question (1) how are you handling the traditional medicine issue in your patients?
   (Probe: what do you tell your patients about using traditional medicine?)

5) What have you heard traditional healers telling clients about the cause of HIV/AIDS?
   (Probe: jealousy, witchcraft)

6) Have you heard of traditional healers prescribing treatment for opportunistic infections?

7) Have you heard of traditional healers violating the rights of their clients?

(Probe: the claim that having sex with a virgin can cure HIV/AIDS, does that come from traditional healers?)

8) Have you treated an HIV positive traditional healer before? How do you perceive the role of the HIV positive traditional healer in bridging the gap between traditional healing and biomedical HIV/AIDS care?

9) What are your feelings about a potential collaboration between traditional healers and formally trained health care workers?

10) Any further comments?

Appendix 3: In-depth Interview Guide (Traditional Healers)

1. How do you view your role as a Traditional Healer in the context of HIV/AIDS?
2. How do you know when someone is HIV positive?
3. How is HIV/AIDS different from other illnesses?
4. HIV/AIDS is a 'new' illness (it was only discovered during the early 1980s) so how does traditional knowledge know how to deal with it?
5. How do you treat HIV/AIDS and opportunistic infections such as TB?
6. Do you use biomedicine? (i.e. do you visit the local clinic, day hospital). What do you think of these types of health care? How do other traditional healers react to you with regard to your beliefs?
7. What do HIV positive patients tell you about the cause of illness?
8. What do you tell HIV positive patients about ARV drugs?
9. What is your opinion of the South African Health Ministry (Manto Tshabalala Msimang) and the way they are handling the issue of HIV/AIDS?
10. Have you any thoughts about the trial of Jacob Zuma and how it has impacted on HIV/AIDS in this country? *
11. How do you see the role of the HIV positive sangoma in bridging the gap between traditional medicine and biomedicine?
12. What would you like the South African government to do to ensure that traditional healers are given a role in the fight against HIV/AIDS?
13. What are your experiences of medical doctors?
14. What do you think about collaboration between Traditional Healers and Medical Doctors?
15. What do you think about collaboration between Traditional Healers and Medical Doctors?

Appendix 4: Patient Questionnaire

Module C: Health, reproductive health and sexual

Interviewer read out: I now want to ask you some questions about your health and relationships.

C.1	In general, how is your health? Would you say it is poor, fair, good, very good or excellent?	Poor	1
		Fair	2
		Good	3
(E.1 CAPS 2005; D.1 KS 2004; D.1 ARV 2004; E.1 KS05)		Very good	4
		Excellent	5
		No response/refused	98
		Don't know	99

C.2	Do you have any health problems or disabilities?	Yes	1	
		No	2	
(E.2 CAPS 2005; E.2 KS05)		No response/refused	98	C.4
		Don't know	99	

			1st Mention	2nd Mention	
C.3	**If the respondent has a health problem or disability, i.e. answered yes to C.2:**	Tuberculosis	1	1	
		Other respiratory problems (asthma, bronchitis, pneumonia)	2	2	
(E.3 CAPS 2005, E.3 KS05)	What is your main health problem?	Physically handicapped	3	3	
		Problems with sight, hearing or speech	4	4	
	Do not read out.	Mental health problem	5	5	
		HIV/AIDS	6	6	
	Circle only one.	Other sexually transmitted disease	7	7	
		Diabetes	8	8	
		Heart disease	9	9	
		Cancer	10	10	
		Epilepsy/fits	11	11	
		Other **(specify)**	12	12	

C.4	Have you been to any of the following in the last month?	E.4.1	Doctor	1	
		E.4.2	Hospital	2	
	Multiple responses allowed.	E.4.3	Clinic	3	
(E.4 CAPS		E.4.4	Traditional Healer/Sangoma	4	

2005; E.4 KS05)		E.4.5	Alternative Healer	5
		E.4.6	None of the above	6
		E.4.7	Other medical attention (**specify**)	7

C.5 (E.5 CAPS 2005; E.5 KS05)	Since the last time we interviewed you in «DATE_OF_INTERVIEW» have **you** suffered any serious illness or injury that stopped you from doing normal activities? If yes, when?	Yes	1	
		No	2	Go to C.7
C.6 (E.6 CAPS 2005; E.6 KS05)	**If yes to C.5, mark the months of serious illness oR Injury on the calendar**			

C.7 (B.8 MSF PANEL STUDY; E.7 KS05)	In the last month, how often did physical disabilities or health problems interfere with your ability to work at a job, look for a job, study, or work around the house	C.7.1	All of the time	1
		C.7.2	Most of the time	2
		C.7.3	Some of the time	3
		C.7.4	A little of the time	4
		C.7.5	None of the time	5

Traditional Medicine						**GO TO**
C.8 (E.8 KS05)	Have you visited a sangoma in the past year?			Yes	1	
				No	2	C.15
C.9 (E.9 KS05)	If yes, how many visits to sangomas have you made in the past year?			None	0	
				Number:		
C.10 (E.10 KS05)	Think back to the last time you visited a sangoma in the past year. Why did you go to the sangoma?					If the respondent says because they were ill or had a problem ask C.10.1
C.10.1 (E10.1 KS05)	What was the illness or problem you were trying to cure?					
C.11 KS05 (A.17 KS 2004; A.17 ARV	Think back to what the sangoma said. [If you visited more than one sangoma, think back to what the last one you visited said.	C11.1	Did the sangoma say that you had been poisoned?	Yes	1	
				No	2	
		C11.2	Did the sangoma recommend that you go to a clinic or visit a doctor?	Yes	1	
				No	2	
		C11.3	Did the sangoma say that you had been bewitched?	Yes	1	
				No	2	
		C11.4	Did the sangoma say that you had been	Yes	1	

2004; E.11 KS05)			bewitched by your mother or a close family member?	No	2
		C11.5	Did the sangoma say that you had angered your ancestors?	Yes	1
				No	2
		C11.6	Other (please specify)	Yes	1
				No	2

						Go to
C.12 (A.18 KS 2004; A.18 ARV 2004; E.12 KS05)	*What treatment were you given?* **Read out**	C12.1	*Medicines to make you vomit*	*Yes*	*1*	
				No	*2*	
		C12.2	*Medicines to clean your blood*	*Yes*	*1*	
				No	*2*	
		C12.3	*Did the sangoma perform or suggest that you perform a ritual to your ancestors*	*Yes*	*1*	
				No	*2*	
		C12.4	*Medicines to stop you being bewitched*	*Yes*	*1*	
				No	*2*	
		C12.5	*Medicines to make you stronger*	*Yes*	*1*	
				No	*2*	
		C12.6	*Medicine to loosen your stools, to make you have diarrhoea*	*Yes*	*1*	
				No	*2*	
		C12.7	*Cuts to your body*	*Yes*	*1*	
				No	*2*	
		C12.8	*Ointment*	*Yes*	*1*	
				No	*2*	
		C12.9	Other (specify)	*Yes*	*1*	
				No	*2*	

C.13 (A.19a KS 2004; A.19a ARV 2004; E.13 KS05)	Did the treatment help at all? **Read out**	Yes – it helped a lot	1	
		Yes – it helped a bit	2	
		It didn't make any difference	3	
		No – it make me feel worse	4	
		No – it made me feel very sick	5	
		I did not receive any treatment	6	
C.14 (E.14 KS05)	How much did the visit to the sangoma cost in total (include the cost of any remedies you had to buy)	R		

C.14a	Was the sangoma aware that you are HIV+? **(Do not read out)**	Yes	1	
		No	2	
		Don't Know	99	
C.14b (ARV04A.20c)	Did the sangoma ask if you were taking any medication?	Yes	1	
		No	2	
C.14c (ARV04 A.20d)	Did you tell the sangoma that you were taking ARVs?	Yes	1	
		No	2	C14f
C.14d (ARV04A.20e)	Did the sangoma tell you to stop taking your ARVs?	Yes	1	
		No	2	C.14f
C.14e (ARV04 A.20f)	If yes, did you stop taking your ARVs?	No	1	
		Yes – for a short time	2	
		Yes – for a long time	3	
C.14f	Did the sangoma give you any treatment you had to swallow?	Yes	1	
		No	2	C15

C.14g (A24 ARV04 – adapted)	When did you take the sangoma's treatment? Interviewer: read out the choices – only circle one.	C14g.1	At the same time I took my ARVs	1	
		C14g.2	An hour before or after I took my ARVs	2	
		C14g.3	Two or more hours before or after I took my ARVs	3	
		C14g.4	Other (explain)	4	
		C14g.5	I cannot remember	99	

C.15 (E.15 KS05)	Have you been to a spiritual healer (umthandazeli) to help you with an illness in the past year?	Yes	1	
		No	2	C.20
C.16 (E.16 KS05)	How many spiritual healers have you visited in the past year?	None	0	
		Number:		
C.17 (E.17 KS05)	Think back to the last spiritual healer you visited (in the past year). Why did you go to the spiritual healer?			If the respondent says because they were ill or had a problem ask C.17.1
C.17.1 (E17.1 KS05)	What was the illness or problem you were trying to cure?			
C.18 (E.18 KS05)	How much did the visit to the spiritual healer cost? (if you have visited more than one, think of the last one you visited)	R		
C.19 (E.19 KS05)	Did the treatment help at all?	Yes – it helped a lot	1	
		Yes – it helped a bit	2	
		It didn't make any difference	3	
		No – it made me feel worse	4	
		No – it made me feel very sick	5	
		I did not receive any treatment	*6*	

C.19a	*Was the spiritual healer aware that you are HIV+?*	*Yes*	*1*	
		No	*2*	
C.19b (ARV04A.20c) – adapted	*Did the spiritual healer ask if you were taking any medication?*	*Yes*	*1*	
		No	*2*	
C.19c (ARV04 A.20d) – adapted	*Did you tell the spiritual healer that you were taking ARVs?*	*Yes*	*1*	
		No	*2*	C19f
C.19d (ARV04A.20e) – adapted	*Did the spiritual healer tell you to stop taking your ARVs?*	*Yes*	*1*	
		No	*2*	C.19f

C.19e (ARV04 A.20f) – adapted	*If yes, did you stop taking your ARVs?*		*No*	*1*	
			Yes – for a short time	*2*	
			Yes – for a long time	*3*	
C.19f	*Did the spiritual healer give you any treatment you had to swallow?*		Yes	*1*	
			No	*2*	*C.20*
C.19g (A24 ARV04 – adapted)	When did you take the spiritual healer's treatment? Interviewer: read out the choices – only circle one.	C19g.1	At the same time I took my ARVs	1	
		C19g.2	An hour before or after I took my ARVs	2	
		C19g.3	Two or more hours before or after I took my ARVs	3	
		C19g.4	Other (explain)	4	
		C19g.5	I cannot remember	99	

C.20 (E.20 KS05)	Have you been to a herbalist in the past year?	Yes	1		
		No	2	C.25	
C.21 (E.21 KS05)	How many herbalists have you visited in the past year	None	0		
		Number:			
C.22 (C.22 KS05)	Think back to the last herbalist you visited (in the past year). Why did you go to the herbalist?		If the respondent says because they were ill or had a problem ask C.22.1		
C.22.1 (E22.1 KS05)	What was the illness or problem you were trying to cure?				
C.23 (E.23 KS05)	How much did you spend on herbal remedies? (if you visited more than one, think of the last one you visited)	R			
C.24 (E.24 KS05)	Did the treatment help at all?	Yes – it helped a lot	1		
		Yes – it helped a bit	2		
		It didn't make any difference	3		
		No – it made me feel worse	4		

We would now like to ask you some questions about your ARV Treatment

D.1	*Are you still taking your ARVs*	Yes	*1*	
		No	2	

D.2 (ARV04 A.9).	If 10 is the healthiest you have been in your life, what score would you give for how you felt:							
D2.1 When you had to start ARVs	10	**D2.2** Three months after the start of ARVs	10	**D2.3** Six months after the start of ARVs	10	**D2.4** How do you feel now?	10	
	9		9		9		9	
	8		8		8		8	
	7		7		7		7	
	6		6		6		6	
	5		5		5		5	
	4		4		4		4	
	3		3		3		3	
	2		2		2		2	
	1		1		1		1	

D.3	What clinic do you get your ARVs from?	Langa	1	Site B	4	
		Hout Bay	2	Michael M	5	
		Paarl	3	Nolungile/Site C	6	
		Other (specify)			7	

D.4	Please tell us about all the CD4 counts that you have had:		**CD4 Count** (Write Number)	Don't Know	**Year** (Write number)		Don't Know	**Month** (Write number)		Don't Know	**D7:** Most Recent
		D4.1		9999	D5.1		9999	D6.1		99	1
		D4.2		9999	D5.2		9999	D6.2		99	2
		D4.3		9999	D5.3		9999	D6.3		99	3
		D4.4		9999	D5.4		9999	D6.4		99	4
		D4.5		9999	D5.5		9999	D6.5		99	5
		D4.6		9999	D5.6		9999	D6.6		99	6
		D4.7		9999	D5.7		9999	D6.7		99	7
		D4.8		9999	D5.8		9999	D6.8		99	8
		D4.9		9999	D5.9		9999	D6.9		99	9

D8	Did respondent use his/her clinic card to remember their CD4 counts?	Yes	1
		No	2

CODES for D6			
January	01	February	02
March	03	April	04
May	05	June	06
July	07	August	08
September	09	October	10
November	11	December	12

D.9a (A13a ARV04) **D.9b** (A13b ARV04)	D.9a. Have you experienced any of the following side-effects from the ARVs in the past three months? D.9b.Did you tell your doctor about the side effect? **Interviewer: read out the questions. Mark yes or no for each one.** **If they answer yes, please ask if they told their doctor about the side effect. Circle '1' if they did.**	D.9b Did you tell your doctor about the side effects?			
				D.9a	D.9b
		D9a.1 Nausea/stomach problems	Yes	1	1
			No	2	2
		D9a.2. Headaches	Yes	1	1
			No	2	2
		D9a.3 Fevers, chills, sweats	Yes	1	1
			No	2	2
		D9a.4 Felt sad or depressed	Yes	1	1
			No	2	2
		D9a.5 Unwanted loss of weight	Yes	1	1
			No	2	2
		D9a.6 Problems with having sex such as loss of interest or lack of satisfaction?	Yes	1	1
			No	2	2
		D9a.7 Skin problems	Yes	1	1
			No	2	2
		D9a.8 Muscle-aches and joint pain	Yes	1	1
			No	2	2
		D9a.9 Pain, numbness or tingling in the hands and feet	Yes	1	1
			No	2	2
		D9a.10 Feeling dizzy and light-headed	Yes	1	1
			No	2	2
		D9a.11 Feeling very tired/exhausted	Yes	1	1
			No	2	2
		D9a.12 Trouble remembering	Yes	1	1
			No	2	2
		D9a.13 Other (specify)	Yes	1	1
			No	2	2

D10: What positive effects have ARVs had on your life?		Yes	No	Don't Know
D10.1	I sleep better than before I started ARVs	1	2	99
D10.2	I have less skin problems	1	2	99
D10.3	I have more strength to earn an income	1	2	99
D10.4	I have less infections	1	2	99
D10.5	ARVs have made me concentrate better	1	2	99
D10.6	My energy has increased	1	2	99
D10.7	I am more positive about my future	1	2	99
D10.8	I am less anxious and worried	1	2	99
D10.9	I will live longer to take care of my children/other children in my household	1	2	99

Adherence (adapted from the Eastern Cape Pilot Survey conducted by Rhodes University and Virginia Commonwealth University).

D.11* (ARV04, A14)	PEOPLE MISS TAKING THEIR ARVs FOR VARIOUS REASONS. IN THE PAST MONTH HOW OFTEN HAVE YOU MISSED TAKING YOUR MEDICATION BECAUSE YOU:				
	(Show card)	Never	Hardly ever	Some-times	Often
	D11.1 Were away from home	1	2	3	4
	D11.2 Were busy with other things	1	2	3	4
	D11.3 Had too many pills to take	1	2	3	4
	D11.4 Wanted to avoid side effects/ thought the drug was harmful	1	2	3	4
	D11.5 Did not want others to see you taking your medication	1	2	3	4
	D11.6 Felt ill or sick	1	2	3	4
	D11.7 Had a change in your daily routine	1	2	3	4
	D11.8 Fell asleep when you should have been taking the pills	1	2	3	4
	D11.9 Felt depressed or overwhelmed	1	2	3	4
	D11.10 Ran out of pills	1	2	3	4
	D11.11 Felt good (did not feel the need for the pills)	1	2	3	4
	D11.12 Forgot	1	2	3	4
D12	On a scale from 1 – 10, where 1 means "I take no pills" and 10 means "I take all my pills", how would you rate your own adherence in the last 3 days? 1 2 3 4 5 6 7 8 9 10				

KNOWLEDGE ABOUT HIV/AIDS AND ARV TREATMENT

This section includes questions about HIV/AIDS and ARV treatment in general. Some of the following statements are true and others are false.

PLEASE DO NOT take these statements as information about HIV/AIDS and ARV medication

Please indicate to what extent you think the following statements are true or false.

D.13*	(Show card)	True	Uncertain	False
D.13.1 (17.1..2 CHSRD 2005)	People receiving ARV treatment can still transmit HIV to other people through unprotected sex.	1	2	3
D.13.2 (17.1.3 CHSRD 2005)	Unprotected sex with withdrawal before ejaculation protects against HIV.	1	2	3
D.13.3 (17.1.4 CHSRD 2005)	One should continue to take ARV treatment after gaining weigh t.	1	2	3
D.13.4 (17.1.5 CHSRD 2005)	It is correct to stop ARV treatment when one no longer suffers from opportunistic infections.	1	2	3
D.13.5 (17.1.7 CHSRD 2005)	ARV medication completely removes HIV from my body.	1	2	3
D.13.6 (17.1.8 CHSRD 2005)	After a couple of years, one can stop taking ARV medication.	1	2	3
D.13.7 (69. ATHRSB 2005)	When both partners are HIV positive there is no need to use a condom	1	2	3

QUALITATIVE AMMENDMENT:

Can you tell me what you have heard about traditional healers in your community? (Probe: Why do you choose not to access a traditional healing service?)

Who do you feel most comfortable discussing issues of traditional medicine with at the clinic?

In-depth Interview Guide (Patients who have visited a traditional healer within the Past Year)

1) What did your traditional healer tell you was wrong with you?
2) What did he or she say was the cause of your illness?
3) Did your traditional healer advise you to go to the clinic to get ARVs? What were his or her reasons for giving you this advice?
4) Did your traditional healer advise you to disclose your HIV status to your family and friends? If Not, then what were his or her reasons? If yes, how did he or she advise you to go about this and what was their advice about quality of life after disclosure of HIV status?
5) Do traditional healers in your community support HIV positive people? If yes how do they encourage support from others? If No, how do they react to HIV positive people?
6) Does your doctor or nurse at the clinic discuss traditional medicine with you? If yes what does he or she advise re: traditional medicine? If no, why do you think he or she does not discuss this issue?
7) Who do you feel more comfortable with at the clinic when it comes to communicating concerns about traditional medicine?

Appendix 6: Informed Consent Form for Health Care Workers

My name is Sumaya Mall and I am currently conducting a study for the Centre for Social Science Research at the University of Cape Town. The study is also part of my Masters degree in Public Health at UCT. The study is investigating the Impact of African Traditional Healers on Antiretroviral Treatment in South Africa.

It would be of great assistance to me if you could participate in this study by allowing me to interview you for about 45 minutes to 1 hour. Your identity will be kept confidential but I am hoping to publish the results in an academic journal. Your participation is voluntary. You may stop the interview at any time.

Many Thanks for your time

Please sign below

Please contact Dr Marc Blockman of the University of Cape Town's Human Ethics Committee should you have any concerns about this study. He can be reached at mblockmn@uctgsh1.uct.ac.za or 021 406 6496 or alternatively my supervisor Prof Leslie London at ll@cormack.uct.ac.za

Appendix 7: Informed Consent Form for Focus Group Participants

My name is Sumaya Mall and I am currently conducting a study for the Centre for Social Science Research at the University of Cape Town. The study is also part of my Masters degree in Public Health at UCT. The study is investigating the Impact of African Traditional Healers on Antiretroviral Treatment in South Africa.

It would be of great assistance to me if you could participate in this study by allowing me to interview you for about 45 minutes to 1 hour. Your identity will be kept confidential but I am hoping to publish the results in an academic journal. You will receive remuneration for your time and information in the form of a R60 food voucher. Your participation is voluntary. You may stop the interview at any time.

Many Thanks for your time

Please sign below

Please contact Dr Marc Blockman of the University of Cape Town's Human Ethics Committee should you have any concerns about this study. He can be reached at mblockmn@uctgsh1.uct.ac.za or 021 406 6496 or alternatively my supervisor Prof Leslie London at ll@cormack.uct.ac.za

Appendix 8: Informed Consent Form for Traditional Healers

My name is Sumaya Mall and I am currently conducting a study for the Centre for Social Science Research at the University of Cape Town. The study is also part of my Masters degree in Public Health at UCT. The study is investigating the Impact of African Traditional Healers on Antiretroviral Treatment in South Africa.

It would be of great assistance to me if you could participate in this study by allowing me to interview you for about 45 minutes to 1 hour. Your identity will be kept confidential but I am hoping to publish the results in an academic journal. You will receive remuneration for your time and information in the form of a R60 food voucher.

Many Thanks for your time

Please sign below

Please contact Dr Marc Blockman of the University of Cape Town's Human Ethics Committee should you have any concerns about this study. He can be reached at mblockmn@uctgsh1.uct.ac.za or 021 406 6496 or alternatively my supervisor Prof Leslie London at ll@cormack.uct.ac.za

Appendix 9: Informed Consent Form for Patients

(Note this questionnaire is currently being used in another study and has already been through Centre for Social Science Research (CSSR) ethics review)

CONSENT FORM

My name is Sumaya Mall and I am currently a Master of Public Health student at the University of Cape Town. I have a scholarship from the UCT Centre for Social Science Research to conduct some research about traditional medicine and ART. I am planning to use this research for my Masters thesis.

You are kindly invited to participate in this study. Before you decide whether to take part, we want to make sure that you understand the following information about the study.

What are the possible benefits of participating?

There will be no direct benefit to you; however the information we obtain from this study will give policy makers a better understanding of the lives of people living with HIV who are taking antiretrovirals. What you have to say could play an important role in improving the lives of people living with HIV, those who need antiretroviral treatment and those who are currently taking treatment- including yourselves.

What are the possible drawbacks or discomforts in participating?

The issue of HIV/AIDS is very personal and sensitive. Some people may find it painful to recall and discuss their own experience.

Do I have to participate?

Your participation in this study is voluntary. Should you agree to participate, you are required to sign this form. You are free to withdraw from the study at any stage and this will in no way affect your ARV treatment.

What will happen to me if I participate?

Information regarding your experience with anti-retrovirals as well as some of the answers you have given your patient advocates will be recorded and treated confidentially.

Will the information be treated confidentially?

Yes, should you agree to participate in the study, all information collected for this study will be kept strictly confidential. Individual responses to our questions will never be made public, and no information which could identify you or your household will ever be released.

Contact details

If you have questions about this interview contact Prof Leslie London, my thesis supervisor at ll@cormack.uct.ac.za or Dr Marc Blockman of the UCT Human Ethics Committee

I, ... (name of respondent in block letters) have read and understood all the information given to me about my participation in this study and I was given the opportunity to discuss it and ask questions. I volunteer to take part in this study. I have received a copy of this consent form.

Signature of respondent	Date

Interviewer: I have:

Explained the nature and purpose of the study to the respondent	N Y	
Handed over a copy of the consent form	N Y	
	Signature of interviewer/fieldworker	**Date**